



**This electronic thesis or dissertation has been
downloaded from Explore Bristol Research,
<http://research-information.bristol.ac.uk>**

Author:
Chavez, Jayne

Title:
**An exploration of the experiences of post-sixteen transition for young people with
autism spectrum disorders.**

General rights

Access to the thesis is subject to the Creative Commons Attribution - NonCommercial-No Derivatives 4.0 International Public License. A copy of this may be found at <https://creativecommons.org/licenses/by-nc-nd/4.0/legalcode>. This license sets out your rights and the restrictions that apply to your access to the thesis so it is important you read this before proceeding.

Take down policy

Some pages of this thesis may have been removed for copyright restrictions prior to having it been deposited in Explore Bristol Research. However, if you have discovered material within the thesis that you consider to be unlawful e.g. breaches of copyright (either yours or that of a third party) or any other law, including but not limited to those relating to patent, trademark, confidentiality, data protection, obscenity, defamation, libel, then please contact collections-metadata@bristol.ac.uk and include the following information in your message:

- Your contact details
- Bibliographic details for the item, including a URL
- An outline nature of the complaint

Your claim will be investigated and, where appropriate, the item in question will be removed from public view as soon as possible.



**This electronic thesis or dissertation has been
downloaded from Explore Bristol Research,
<http://research-information.bristol.ac.uk>**

Author:

Chavez, Jayne

Title:

**An exploration of the experiences of post-sixteen transition for young people with
autism spectrum disorders.**

General rights

Access to the thesis is subject to the Creative Commons Attribution - NonCommercial-No Derivatives 4.0 International Public License. A copy of this may be found at <https://creativecommons.org/licenses/by-nc-nd/4.0/legalcode>. This license sets out your rights and the restrictions that apply to your access to the thesis so it is important you read this before proceeding.

Take down policy

Some pages of this thesis may have been removed for copyright restrictions prior to having it been deposited in Explore Bristol Research. However, if you have discovered material within the thesis that you consider to be unlawful e.g. breaches of copyright (either yours or that of a third party) or any other law, including but not limited to those relating to patent, trademark, confidentiality, data protection, obscenity, defamation, libel, then please contact collections-metadata@bristol.ac.uk and include the following information in your message:

- Your contact details
- Bibliographic details for the item, including a URL
- An outline nature of the complaint

Your claim will be investigated and, where appropriate, the item in question will be removed from public view as soon as possible.

An exploration of the experiences of post-sixteen transition for young people with autism spectrum disorders

Jayne Chavez

A dissertation submitted to the University of Bristol in accordance with the requirements for award of the Degree of Doctor of Educational Psychology in the Faculty of Social Sciences and Law.

February 2019

Words: 46,953.

Abstract

This study explores the experiences of post-sixteen transition for young people with autism spectrum disorders. This is a two-part study which captures their experiences prior to leaving secondary school and again when they are engaged in post-sixteen education. There is a lack of research that includes the voices of adolescents with autism as they approach and navigate this important transitional period.

Semi-structured interviews were conducted with the participants. The first interviews took place when the young people were in their final year of secondary education (Year 11) in which they recall their experiences during this time and their preparations for transition. The second interviews were conducted when the participants had enrolled on a further education course (Year 12) and these describe their current situation as well as exploring transition retrospectively.

The chosen methodological approach was Interpretative Phenomenological Analysis. The idiographic commitment of the approach allowed the unique experience of the participants to be explored as well as observing the experiences, or themes, that connected them. The pre-transition master themes that emerged from the study were: Relationships, understanding self and the future. The post-transition themes were: Continuation and the past. These themes were influenced by the over-arching theme of Adolescence.

The findings of the study indicate that young people with autism can find post-sixteen transition to be a time that presents opportunity but also creates new challenges. Gaps in processes around transition and the particular features of the further education environment can enhance these challenges. Findings were applied to Bronfenbrenner's Bio-ecological systems model (1994) which can provide a framework for intervention for professionals and create a shared understanding of the wide range of needs and influences in the lives of young people with autism. Recommendations have been suggested for adults to consider, when working with young people during this transition period.

Acknowledgements

I would like to express my sincere thanks to all the people who have made this dissertation possible. I am grateful to the participants who selflessly volunteered their time at a busy period in their lives. Their stories have reinforced the importance of understanding and valuing the lives of individuals. We always have something to learn from each other.

I am also extremely thankful for the support of all the tutors on the Doctorate in Educational Psychology course, throughout my time on the programme. I would like to offer special thanks to Dr John Franey, my dissertation supervisor, who has been a calm and much valued presence throughout this journey.

I would also like to thank my family for their constant love and support over the course of the programme. They have continued to inspire and energise me throughout.

Without these people, this journey would not have been possible.

Author's Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's *Regulations and Code of Practice for Research Degree Programmes* and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

SIGNED:.....

DATE:.....

Table of Contents

Abstract.....	1
Acknowledgements.....	2
Author's declaration.....	3
List of tables.....	9
List of figures.....	9
1. Introduction.....	10
1.1. Chapter overview.....	11
1.2. Current context.....	11
1.3. Legislative background.....	12
1.4. Personal and professional background to the study.....	15
1.5. Rationale for the research.....	16
1.6. Methodological orientation.....	17
1.7. Research aims and questions.....	18
1.8. Questions of definition and terminology.....	18
1.9. The structure of the study.....	20
2. Literature Review.....	22
2.1. Chapter overview.....	23
2.2. Literature search.....	23
2.3. Understanding the autism spectrum.....	24
2.4. Key literature.....	25
2.5. Literature: Pre-transition to post-transition period.....	26
2.5.1. Adolescence.....	26
2.5.2. Social and emotional wellbeing.....	28
2.5.3. Identity.....	29
2.5.4. Fitting In.....	31
2.5.5. Independence.....	33
2.5.6. Aspirations.....	34
2.6. Literature: The pre-transition period.....	35
2.6.1. Disabling environments.....	35
2.7. Literature: The transition period.....	36

2.7.1.	The opportunities and challenges of the transition period.....	36
2.7.2.	The process of transition – views from young people.....	38
2.7.3.	The process of transition – an international context.....	42
2.8.	Literature: Post-transition period.....	45
2.8.1.	Life in further education.....	45
2.9.	Specific challenges for young people with ASD during the period of post-sixteen transition.....	47
2.10.	Conclusion and research aims.....	48
3.	Methodology.....	50
3.1.	Chapter overview.....	51
3.2.	Choosing a qualitative research approach.....	52
3.3.	Choice of methodology.....	53
3.3.1.	Phenomenology.....	55
3.3.2.	Interpretation.....	55
3.3.3.	Analysis.....	56
3.4.	The Research Design.....	57
3.4.1.	Participants – selecting a sample.....	57
3.4.2.	Initial stages of recruitment and informed consent.....	57
3.4.3.	Further considerations in recruitment.....	58
3.4.4.	Recruiting a sample.....	59
3.4.5.	Anonymity and confidentiality.....	61
3.5.	Research Processes.....	61
3.5.1.	Choice of method.....	61
3.5.2.	The interview process.....	62
3.5.3.	Data analysis.....	64
3.6.	Critique of methodology.....	66
3.7.	The role of language in qualitative research.....	67
3.8.	Ethical practice.....	68
4.	Findings.....	70
4.1.	Chapter overview.....	71
4.2.	Jack’s story: Pre-transition.....	71
4.2.1.	Self-perceptions.....	72
4.2.2.	Finding answers.....	73

4.2.3. Leaving secondary.....	74
4.3. Jack's story: Post-transition.....	75
4.3.1. Moving on.....	75
4.3.2. Relationships.....	77
4.3.3. Adjustment.....	79
4.4. Tom's story: Pre-transition.....	80
4.4.1. Developing self-awareness.....	81
4.4.2. Future planning.....	82
4.5. Tom's story: Post-transition.....	84
4.5.1. Moving on.....	84
4.5.2. New experiences.....	85
4.6. Adam's story: Pre-transition.....	87
4.6.1. Relationships.....	87
4.6.2. Planning.....	89
4.7. Adam's story: Post-transition.....	90
4.7.1. Continuation.....	90
4.7.2. Into the future.....	91
4.8. Matt's story: Pre-transition.....	92
4.8.1. Understanding.....	93
4.8.2. The future.....	94
4.9. Findings at group level: Pre-transition master themes.....	96
4.9.1. Relationships.....	97
4.9.2. Understanding self.....	99
4.9.3. The future.....	100
4.10. Findings at group level: Post-transition master themes.....	103
4.10.1. Continuation.....	103
4.10.2. The past.....	105
4.11. Chapter Summary.....	107
5. Discussion.....	108
5.1. Chapter overview.....	109
5.2. Addressing research questions.....	110
5.2.1. Over-arching theme: Adolescence.....	111
5.3. Pre-transition experiences.....	112

5.3.1. Relationships.....	112
5.3.2. Understanding self.....	115
5.3.3. The future.....	115
5.4. Post-transition experiences	117
5.4.1. Continuation.....	117
5.4.2. The past.....	118
5.5. Question 1: What has been your experience of post-sixteen transition?.....	119
5.6. A summary of the findings: Research questions 2 and 3.....	121
5.7. Findings related to the existing literature.....	123
5.7.1. Adolescence.....	125
5.7.2. Findings which support the current literature.....	126
5.7.3. Findings which are more distinctive to the current study.....	134
5.7.4. The transition period.....	139
5.7.5. Life in further education.....	141
5.8. Strengths of the study.....	145
5.9. Limitations of the study.....	146
5.10. Wider implications for intervention.....	147
5.11. An intervention framework - Bio-ecological systems theory.....	147
5.12. Implications for Educational Psychologists.....	155
5.13. Implications for wider systems.....	156
5.14. Implications for research.....	158
5.15. Summary of the chapter.....	159
6. Conclusion.....	161
6.1. Chapter overview.....	162
6.2. Assessing qualitative research.....	162
6.2.1. Sensitivity to Context.....	162
6.2.2. Commitment and Rigour.....	163
6.2.3. Transparency and Coherence.....	164
6.2.4. Impact and importance.....	164
6.3. Reflexivity.....	165
6.4. Reflections on the research process.....	166

References.....	167
Appendices.....	182
Appendix 1: Literature search strategy.....	186
Appendix 2: Inclusion criteria for the participants.....	189
Appendix 3: Pre-visit information for potential participants.....	190
Appendix 4: Pre-visit letter to parents.....	191
Appendix 5: Letter to Head Teacher.....	192
Appendix 6: Information and Consent sheet for participants.....	194
Appendix 7: Information and Consent sheet for parents.....	198
Appendix 8: Topic guide for participants for the pre- and post-transition interview.....	201
Appendix 9: Interview schedule for pre-transition interview.....	203
Appendix 10: Interview schedule for post-transition interview.....	204
Appendix 11: ‘Useful websites’ for the participants.....	205
Appendix 12: Example of steps 2 and 3 in data analysis.....	206
Appendix 13: Email confirming ethical approval.....	209

List of Tables

Table 1: Details of the participants in the study.....	60
Table 2: Pre-transition super-ordinate and sub-themes for Jack.....	71
Table 3: Post-transition super-ordinate and sub-themes for Jack.....	75
Table 4: Pre-transition super-ordinate and sub-themes for Tom.....	80
Table 5: Post-transition super-ordinate and sub-themes for Tom.....	84
Table 6: Pre-transition super-ordinate and sub-themes for Adam.....	87
Table 7: Post-transition super-ordinate and sub-themes for Adam.....	90
Table 8: Pre-transition super-ordinate and sub-themes for Matt.....	93
Table 9: Master themes from the pre-transition interviews.....	96
Table 10: Master themes from the post-transition interviews.....	103
Table 11: Erikson's Psychosocial stages.....	111
Table 12: A summary of the participants' experiences of post-sixteen transition....	119
Table 13: Positive and negative factors associated with the participants' transition.	122
Table 14: Intervention at microsystem and mesosystem levels.....	149
Table 15: Record of databases searched.....	186
Table 16: Inclusion criteria for the participants.....	189

List of Figures

Figure 1: Pre-transition and post-transition master themes.....	110
Figure 2: Pre-transition master themes.....	112
Figure 3: Post-transition master themes.....	117
Figure 4: Bio-ecological systems theory (1994).....	148
Figure 5: Flow diagram outlining the literature review process.....	188

Chapter 1

Introduction

1.1. Chapter overview

This research was conducted as part of a three-year doctoral programme in Educational Psychology at the University of Bristol.

The aim of this chapter is to:

- Introduce the subject area of the research.
- Place the study in terms of its current context regarding post-sixteen education.
- Provide a legislative background relevant to young people with autism in education.
- Outline the personal significance of the study.
- Affirm the research questions as well as define key terms used within the study.
- Give an overview of the chapters in the dissertation.

1.2. Current context

Given the right support, young people with autism can – and do- thrive and succeed. (Ambitious for Autism, 2011).

The numbers of young people in further education in the United Kingdom identified as having an autism spectrum disorder (ASD) has increased significantly over the last ten years (DfE, 2018a). This has been related to a steady rise in the numbers of children and young people diagnosed with ASD, a pattern which has been established over the last two decades, (Brugha, Cooper, McManus, Purdon, Smith, Scott, Spiers and Tyrer, 2012) as well as a changing policy context within education (DfE, 2008).

It is estimated that the figures for individuals on the autism spectrum now equate to 1.1% of the population (Brugha et al, 2012). There are a number of reasons proposed for the rise in diagnoses but better recognition of the symptoms of autism, as well as some 'relaxation' in the diagnostic criteria have been offered as partial explanations (Baird, Siminoff, Pickels, Chandler, Loucas, Meldrum and Charman, 2006). There is a gender imbalance in diagnosis and autism spectrum conditions are far more common in males than females, with 'classic autism' occurring in four males for every female and Asperger's Syndrome in nine males for every one female (Baron-Cohen, 2008).

According to recent figures (Council for Disabled Children, 2018) this rise means that the number of children and young people with an Education, Health and Care Plan, whose main need was autism spectrum disorder rose by 54% in primary schools and 182% in secondary schools between 2014 and 2018. Differences in local authority practice regarding statutory processes will have an implication on the amount and type of support available for children and young people on the autism spectrum (Beardon, Martin and Woolsey, 2009).

In 2009, one in four young people with autism continued education after secondary school (Ambitious for Autism, 2011) but legislation which now requires all young people to stay in education or training until eighteen years old (DfE, 2008) has resulted in a significant rise in the numbers attending a range of further education provisions. Published figures from the Department of Education (2018a) reveal that 91% of young people with an autism diagnosis, were in a sustained (over six consecutive months) education destination in Key Stages 4 and 5 during the years 2016/ 2017. This compared to 87% of all young people. This included mainstream and specialist provision. A limited number of specialist education placements (Council for Disabled Children, 2018) indicates that a high proportion of these young people will be enrolled at mainstream further education colleges.

1.3. Legislative background

Improvements have been made over time in terms of legislative protection for children and young people with special educational needs in education and more broadly. The Equality Act (2010) requires educational settings to make 'reasonable adjustments' and 'prevent children being put at a substantial disadvantage' (DfE, 2015, p93). The Care Act (2014) relates more directly to the wider support and care needs of individuals and aims to give greater control and influence for those in need of support.

The Children and Families Act (DfE, 2014a) and the resulting statutory guidance, has outlined the extended duties of organisations in protecting the rights of young people up to the age of twenty-five years old. The 'Special Educational Needs and Disability Code of Practice: 0-25 years (DfE, 2015a) has established core principles in this work including: the importance of hearing the 'voice' of the child, young person and family throughout

education; an increased focus on preparing for adulthood at an earlier stage in the lives of young people and more attention to the progress and outcomes of young people.

The Autism Act (2009), the only autism-specific legislation, focuses on the rights of the adult population with autism. The Adult Autism Strategy 'Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England' (DOH, 2010) was updated by 'Think Autism' (DfE, 2014c) to ensure the effective implementation of the Act (Department of Health, 2015). The unique needs of children and young people with autism however have not currently been addressed in the same way, through legislation.

The ability of educational provisions to meet the needs of young people with autism is an ongoing concern (Jones, English, Guldberg, Jordan, Richardson, Walt, 2009; All-Party Group for Autism, 2017). There is increasing recognition of the areas of difficulty associated with the autism spectrum, which include: Social Communication, social interaction, imagination and sensory (Baron-Cohen, 2002) and this has led to a view that educational environments can be 'disabling' for some of these young people (Humphrey and Lewis, 2008). The high rate of exclusions from schools in the United Kingdom has become an increasing cause of concern (Reid, 2011) with 17% of autistic children having been suspended from school; 48% of these had been suspended three or more times and 4% had been permanently excluded from one or more schools.

Established charitable organisations and lobbying groups have been contributing to an evidence base in reporting the experiences of children and young people and their families and guidelines for professionals have been provided in response to this (DfES, 2002; Autism Education Trust, 2017). There is general agreement that some progress has been made in educational settings but that there is still a considerable distance to go in meeting the needs of all children and young people with autism across educational stages (Ofsted, 2016; APPGA, 2017).

Increasing understanding of the range of difficulties experienced by individuals with autism, has raised interest and concerns around transitional periods (Mitchell and Beresford, 2014). It is acknowledged that transition can introduce a specific range of challenges (DfES, 2002). The challenges relating to post-sixteen transition may have some unique features, and for young people with autism they are often required to attend

mainstream further education colleges to continue their post-secondary education, with a lack of suitable alternatives being available (Ambitious for Autism, 2011).

The Code of Practice (2015a) acknowledges the vulnerabilities of all young people with special needs during this transitional period and establishes the importance of early planning.

For children and young people with EHC plans, discussions about post-16 options will be part of the preparing for adulthood focus of EHC plan reviews, which must be included as part of the review from Year 9 (p120).

It also recognises the need for support to be provided by educational establishments specifically related to transition periods:

SEN support should include planning and preparation for the transitions between phases of education and preparation for adult life (p102).

As children approach the transition point, schools and colleges should help children and their families with more detailed planning (p129).

There has been an increasing focus on the outcomes for children and young people with additional needs as they move into adulthood (DfE, 2015a). Poor long-term outcomes have increasingly become a concern (Ofsted, 2012). Findings in research which has focused on adult outcomes for individuals on the autism spectrum have been particularly alarming (Howlin, Goode, Hutton and Rutter, 2004; Barnhill, 2007; Howlin and Moss, 2012) with widely reported figures on employment rates for adults with autism, of 16 % of adults in full-time employment and 32% in part-time and full-time employment combined. This is compared to 47% of people with other disabilities (National Autistic Society, 2016). The role of further education colleges has gained special attention in the drive to improve outcomes.

In August 2012, the Ofsted survey 'Progression for post-16 for learners with learning difficulties and/or disabilities' reported a number of concerns with post-sixteen provision. These included:

- Transition arrangements for these learners to post-16 education and into adulthood were not fully effective.

- Schools, local authorities and other agencies did not work together sufficiently well to ensure that learners were adequately prepared for transition between school and post-16 provision.

Concerns have continued regarding the ability of further education providers to meet the needs of 'high-needs' learners in preparing them for adult life (Ofsted, 2016). Ofsted inspectors reported that only eight of the 17 providers visited were fully equipped to support the increased enrolment figures of 'high needs' learners. This related to inadequate provision of specialist resources and a lack of effectively trained staff (p7). The quality of provision for learners with high needs was also often not of a high enough standard and it lacked meaningful work experience to support young people to meet their goals (p7). A new inspection framework for further education provision has recently been established (Ofsted, 2018).

Guidelines supporting schools and colleges to meet the unique needs of young people with autism have been published more recently (DfE, 2015b). The Autism Education Trust (2018a) have published a further set of guidelines. 'A Competency framework' relates to 'core' practice competencies for all staff and 'advanced' practice competencies for staff who have a lead role in 'championing' autism within college. 'Post-sixteen autism standards' (AET, 2018b) is an accompanying document. The recent publication of these guidelines suggests that institutions may not have had sufficient time to fully implement them. The changing landscape of further education and the ability of further education providers to meet the needs of young people with autism remains a very significant concern.

1.4. Personal and professional background to the study

My personal interest in researching post-sixteen transition for young people with autism has developed from my work as a Connexions Advisor. Part of this role involved providing information, advice and guidance to young people with autism, who accessed a resource-based provision for students with social and communication difficulties, attached to a mainstream secondary school. For most of these young people, at the end of secondary school, they moved onto a specialist further education college. Partly due to changes in the funding of further education including the demise of the Learning and Skills Council

(Department for Universities, Innovation and Skills, 2008), and increasing financial pressures on the local authorities, over time more of these young people were required to attend mainstream further education college. This introduced challenges for both them and the colleges, who were relatively unfamiliar with managing young people with, what they considered to be, a specific and significant level of need.

More 'open' discussion about the autism spectrum over time, has prompted my interest in understanding the wider experiences of those on the autism spectrum. This was enhanced after my own son received a diagnosis during this time, and this led to a professional, but also a very personal, quest to increase my understanding of the 'lived experiences' of young people with autism, across a range of areas.

1.5. Rationale for the research

The aim of the study is to understand the experience of post-sixteen transition from the unique perspective of individuals who are experiencing it. In recognition of the increasing numbers of young people with autism in mainstream education, I was interested to explore this from the perspective of those who were moving onto mainstream further education colleges (Breakey, 2006).

Exploring the voice of the young person was an important aspect of this research, as advocated in a range of literature, and observed to be a gap in research, particularly with adolescents on the autism spectrum (Parsons, Guldberg, MacLeod, Jones, Prunty and Balfe, 2011). Challenges have been noted in qualitative research with young people with autism, and the use of interviews with these young people has been limited (Nicholas, Hodgetts, Zwaigenbaum, Smith, Shattuck, Parr, Conlon, Germani, Mitchell, Sacrey and Stothers, 2017). It was critical as a researcher to challenge possible stereotypical assumptions that young people with autism were unable to make their views known, and it was a further aspiration that involving young people in research would be empowering for them (Robinson and Kellett, 2004). Growing numbers of studies have indicated that young people with autism are able to competently engage with adults and can effectively reflect on their experiences if a suitable respectful and non-judgemental environment is provided (Beresford, Tozer, Rabiee and Sloper, 2007).

In defining my research area further, I initially performed a brief literature search which identified a gap in knowledge of the 'lived' experience of young people transitioning into further education. I arranged meetings with the Special Educational Needs Co-ordinator at a local college, and members of college staff with specific responsibility for the students with autism. These meetings confirmed that there had been a significant increase in the numbers of students with diagnosed and potentially undiagnosed autism spectrum disorder entering the college. There was a sense in our conversation that the increased numbers of students had led to a staffing crisis, in that the college were struggling to meet the needs of the students with the current numbers and expertise of the staff.

We discussed some of the challenges that these students were experiencing within the further education environment, and features of the transition process between secondary and further education that supported and hindered them. This prompted my interest in developing a two-part study to capture the unique perspective of these young people as they moved from one provision to another. This would hopefully offer some insight into aspects of the transition process, from the perspective of students, for whom change is a well-known area of difficulty (Wing, 1996).

1.6. Methodological orientation

In order to effectively address my research questions and seek to genuinely understand the experiences of the participants, I chose a methodological approach that stresses the importance of phenomenology in understanding an individual's experience existing in the 'real world' (Willig, 2013, p16). The approach of Interpretative Phenomenological Analysis (IPA) felt appropriate in that it is a well-recognised method in research with individuals in vulnerable groups (Todovora, 2011). It also acknowledges that a level of interpretation is an essential aspect of understanding. The uniqueness of interpretation in this method for Smith (2011) is that the researcher in IPA engages in a 'double hermeneutic', attempting to make sense 'of the participant trying to make sense of what is happening to them'. In my mind, this suggests a more egalitarian premise, in that the researcher is approaching from a position of curiosity in valuing the individual's perceptions of an experience.

This methodology supports my epistemological stance in recognising that there is not only one version of reality but many different versions. This is consistent with a constructivist paradigm in that human beings construct their own knowledge and understanding from their own experiences. Each participants' experiences prior to transition, during the immediate transition period and following, will be unique (Larkin, Watts, and Clifton, 2006; Smith, Flowers and Larkin, 2009). Data analysis would follow the process as outlined in Smith et al. (2009, p82). This relies on a real personal commitment to achieve sufficient depth and quality of analysis in discovering individual and joint themes (Larkin et al, 2006). I approached this research prepared for an intellectual and a potentially emotional challenge.

1.7. Research aims and questions

The aim of the study was to explore post-sixteen transition from the unique perspective of the participants. The first research question was deliberately broad in order to capture diverse aspects of their experience. Questions two and three were more specific, hoping that information acquired could further support the practice of adults working with young people with autism during this time. The research questions that I hoped to answer were:

- 1) What has been your experience of post-sixteen transition?
- 2) Have there been any factors that have had a particularly positive effect on your experience?
- 3) Have there been any factors that have had a particularly negative effect on your experience?

In my study I was interested to explore transition in terms of the changes which young people may experience during this time and was using the term in its broadest sense to capture as many different aspects of the experience as possible. I have accepted the meaning of transition as 'the process or a period of changing from one state or condition to another' (<https://en.oxforddictionaries.com/definition/transition>).

1.8. Questions of definition and terminology

In this section I will outline some of the key terms used within the study.

Post-sixteen – This term describes the period after 16 years old. For young people in England this usually means finishing compulsory secondary education.

Year 11 - This is the last year of secondary education.

Year 12 – This is the first year of post-secondary education.

Further education – This term includes education that follows secondary education. It is usually accessed either in a sixth form provision within a secondary school, a sixth form college or an independent further education college.

Higher education – This term describes education after the age of eighteen, which takes place in a range of institutions including further education colleges but more often in universities.

Neurotypical - This is a neologism widely used in the autistic community as a label for people who are not on the autism spectrum.

Understanding the Autism Spectrum

I have used the term autism spectrum disorder in my study, in recognition of the changes in the diagnostic manual, DSM-V (APA, 2013). This has brought together a range of different diagnoses that have been used in the past. In DSM-V (APA, 2013), the terms 'autistic disorder', 'Asperger disorder', 'childhood disintegrative disorder' and 'Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)' have been replaced by the collective term 'autism spectrum disorder'.

According to the National Autistic Society the fact that it is now categorised within the DSM-V 'means that it's likely that 'autism spectrum disorder' (ASD) will become the most commonly given diagnosis' (<http://www.autism.org.uk/about/diagnosis/criteria-changes.aspx>).

There are still other diagnostic manuals currently being used. In the United Kingdom, the ICD-11 (WHO, 2018), is the most commonly used manual, and the recently revised edition has now aligned with the DSM-V, by using the term 'Autism Spectrum Disorder'. However, clinicians may still use additional terms to help to describe the particular autism profile presented by an individual.

There have been ongoing debates regarding the understanding of autism and the use of the term autism spectrum disorder (ASD). One discussion relates to the description of autism as a 'different' style of cognition rather than as a 'disorder' (Molloy and Vasil, 2002; Baron-Cohen, 2002). For many, using the language of disorder or impairment is consistent with deficit-thinking, and may imply that people with this condition are 'less than' their neurotypical counterparts (Milton, 2014). I would acknowledge that this term has ethical implications. Within my writing the term ASD is used in keeping with the literature around the topic, and to create a shared understanding rather than as an agreement that the language of disorder is acceptable. I acknowledge that ASD covers a spectrum of need and also use the term 'autism' or 'autism spectrum' in recognition that these terms are more typically used today (AET, 2017, p73)

1.9. The structure of the study

To conclude, I will outline the structure of the dissertation. This chapter has summarised the significance of the topic of post-sixteen transition and some of the related issues. This includes the changing landscape of further education for young people with additional needs, and new guidelines and legislation that has been introduced to provide greater protection for these young people. The unique needs of young people with autism have been briefly outlined. I have also highlighted my personal interest in this topic and described how I reached a decision to complete my doctorate study on this topic. The research aims have been identified, as well as an explanation for the choice of methodological approach. The selection of Interpretative Phenomenological Analysis (IPA), was made because of its ideographic emphasis and its focus on phenomenology and interpretation. I have also stated the research questions for the study.

In Chapter 2, I review the literature in the area of post-sixteen transition, which includes the period prior to the physical transition to further education college, as well as the time immediately following.

In Chapter 3, I explain the methodological approach of the study in more detail. I then outline the processes involved in recruiting participants and describe the different stages that were involved in conducting the research.

In Chapter 4, I outline the findings in the research by describing the individual themes that emerged, as well as the joint themes that were shared by the participants.

In Chapter 5, I discuss the findings in terms of the current research identified in the literature review, as well as including other literature that may be related to themes that have emerged in the findings.

Finally, in Chapter 6 I include my personal reflections on the research process and my experience of being a qualitative researcher.

Chapter 2

Literature Review

2.1. Chapter overview

In the previous chapter I introduced the subject area of the study. I outlined the research questions, highlighted legislation that is relevant to the topic, and confirmed the personal and professional significance of the study. This chapter aims to explore the literature in relation to the period of post-sixteen transition as experienced by young people with autism spectrum disorders, as they leave secondary school and move onto further education.

This chapter aims to:

- Describe the literature searches undertaken.
- Outline key features associated with the autism spectrum in order to create a shared understanding.
- Highlight general issues related to the key literature in this topic area.
- Explore the themes that have developed in the literature concerning young people with autism over this period.
- Provide a rationale for the current study.

2.2. Literature search

A systematic literature search was conducted, using a range of different electronic databases. These included: PsycINFO, British Education Index, Education Resources Information Centre (ERIC), Child Development and Adolescent Studies, Web of Science and Electronic Theses Online System (ETHOS).

A number of key search terms were established to search these databases, in order to identify relevant literature for this study. The results of the databases searched, and the key terms used, are listed in Appendix 1. Key Educational Psychology journals such as 'Educational Psychology in Practice' and 'Educational and Child Psychology' were searched separately in order to ensure that no key articles or pieces of literature were missed. A set of inclusion and exclusion criteria were used (see Appendix 2) in order to select the relevant literature to use within the literature review.

Initially only studies from the United Kingdom were selected, but there is a limited amount of research specifically focusing on this group. Research is more prolific in the

USA, Canada and Australia, where certain processes involving transition with young people on the autism spectrum are more established and supported by legislation (IDEA, 2004). I have included some key studies from these parts of the world that are within the parameters of the inclusion criteria and contribute to the general evidence base. The educational system and transition processes may differ in these countries, but there are similarities in the needs of young people with autism regardless of the country they live in. An increase in studies that seek to identify the views of adolescents has been seen since 2000, so I have mainly excluded studies from before this time.

Seminal texts, grey literature, government documents and reports and websites relevant to the study were also used, as well as some doctoral research. Relevant texts were also identified through 'snowballing' where articles have been cited in other texts which were deemed relevant to the study. Further references were then followed up from these texts (Jalali & Wohlin, 2012). The main searches took place between September 2016 and May 2017, although searches were regularly repeated throughout, to ensure that the results were as current as possible.

2.3. Understanding the autism spectrum

Autism is a spectrum condition which means that all autistic people share certain difficulties but being autistic will affect them in different ways. It is estimated that there are around 700,000 people on the autism spectrum in the United Kingdom, more than one per cent of the population (NAS, 2018). The DSM-V (APA, 2013) defines autism spectrum disorder as "persistent difficulties with social communication and social interaction" and "restricted and repetitive patterns of behaviours, activities or interests" (this includes sensory behaviour), present since early childhood, to the extent that these "limit and impair everyday functioning" (<http://www.autism.org.uk/about/diagnosis/criteria-changes.aspx>).

Autism spectrum disorders are often accompanied by co-morbid conditions such as: anxiety, depression and Obsessive Compulsive Disorder.

It is recognised that around fifty percent of individuals who meet the diagnostic criteria for ASD have an IQ within the normal range or above (Baird et al, 2006).

Autism spectrum disorder is a relatively recent diagnostic category (APA, 2013; WHO, 2018) and young people who may be considered to have an autism spectrum disorder today may have originally received a different diagnosis. This suggests that the profile of young people who now fall within this category will vary, but there are some common areas of difficulty for all individuals with an autism spectrum disorder. The implications of the changing diagnostic criteria when reviewing research in this area is acknowledged within this chapter. The wider impact in terms of policy and practice is discussed at different points in the study.

2.4. Key literature

In exploring this topic area, it has become apparent that there is a significant amount of literature which exists around the difficulties of transition for young people on the autism spectrum (DfE, 2002; Baron-Cohen, 2002). Transition between primary and secondary school has been a particular focus in research (Dann, 2011; Dillon and Underwood, 2012). There is a small body of literature which covers the challenges of young people with ASD within secondary education (Connor, 2000; Humphrey and Lewis, 2008) but considerably less, in the United Kingdom, which covers the period of transition from secondary school.

Much of the literature relating to this period has emanated from the USA or, to a lesser degree, other parts of the world where their educational system is different to the United Kingdom. The transition process has received a greater amount of attention in the USA where it has been formalised for longer within legislation (IDEA, 2004). A school system in these countries often means that young people leave compulsory education later than their UK counterparts, and sometimes not until eighteen years of age depending to some degree on local laws.

Many studies concern themselves with the transition to further education and higher education within the same study, suggesting that there may be more similarities than differences (Toor, Hanley and Hebron, 2016). It could also indicate however that the differences between them have not been adequately recognised (OECD, 2011).

In acknowledging the changes in the categorisation of autism within the DSM-V (APA, 2013), it is important to recognise that, for some time, the further education college population has been composed of individuals with a wide range of needs. This includes

those with autism and accompanying learning difficulties who now fall into the wider category of ASD. Within the literature, this group may previously have been subsumed within the broader categories of individuals with more complex needs (Preece, 2002; Kelly, 2005), and to some degree this will continue to be the case. This has created some challenges when trying to identify relevant studies for inclusion or compare findings between studies. There is some agreement that the needs of this group vary considerably to those with average IQ levels (Baird et al, 2006).

I will now explore the themes that have developed in the literature concerning young people with autism over this period. To provide further structure to this review I have divided the literature into a time frame related to the transition period.

This includes:

- Literature that covers a broad time span, encompassing pre-transition to post-transition periods.
- Literature that is more specifically related to the pre-transition period.
- Literature that is mainly concerned with a narrower period of transition (Year 11 to year 12).
- Literature that more clearly covers the post-transition period.

It must be acknowledged that there is a degree of overlap between these time periods, but for ease of understanding the literature can be broadly categorised in this way.

2.5. Literature: Pre-transition to post-transition period

2.5.1. Adolescence

There is some consensus in the literature related to post-secondary transition that this period can be described as a time of moving towards adulthood (Hendricks and Wehman, 2009; Rydzewska, 2012) and this has some similarities to the definition of 'adolescence' (Siegel, 2013). In acknowledging this, I believe it is necessary to situate this period of transition within the developmental stage at which it takes place. This may help us to fully appreciate the challenges and opportunities that it may present for young people on the autism spectrum.

A wide range of literature supports the view that the period of adolescence can be a challenging time for many young people (Siegel, 2013). It is a period characterised by biological change alongside increasing academic and social demands. Many writers recognise it as a time when young people question their current identity during a period of increasing independence from parents (Erikson, 1968). Peer relationships take on a new significance, with romantic relationships often developing during this time. Social comparisons and 'fitting in' with peers are important aspects of adolescence (Huws and Jones, 2015; Acker, Knight and Knott, 2018). The definition of adolescence as a 'transitional phase of growth and development between childhood and adulthood' (www.britannica.com) does not adequately describe the turbulence that some psychologists attach to this period (Erikson, 1968).

For some (Rydzewska, 2012; Arnett, 2000), viewing adolescence as a stage between childhood and adulthood does not take account of features within the current social and economic climate. It is suggested that a linear pattern of development between childhood and adulthood is less typical than in the past.

Today, most young people's individual biographical timetables no longer follow socially expected and culturally transmitted age norms. The borders between all phases of the life course have become blurred and fuzzy. (Rydzewska, 2012, p91).

For Rydzewska (2012) this makes young people with additional needs more vulnerable because further obstacles may be created for them as they progress through adolescence.

A general overview of factors associated with adolescence may help us to understand the environment that a young person on the autism spectrum will inhabit, with an acknowledgement that transition to post-sixteen education will take place during this time. Significant factors include:

- The increasing influence and importance of peers.
- Heightened academic pressures during this period.
- Expectations of increasing independence.
- Uncertainties related to future pathways.
- The impact of physical and physiological changes.

2.5.2. *Social and emotional wellbeing*

For some young people, adolescence can be period when social and emotional wellbeing can be compromised, and mental health difficulties may emerge (Centre Forum, 2016). In recent years there have been increasing concerns around the mental health of young people in the United Kingdom (Weare, 2015).

Research suggests that young people on the autism spectrum can find adolescence a particularly challenging period and can be more vulnerable to mental health difficulties than their neurotypical peers during this time (Browning, Osborne and Reed, 2009; Kim, Szatmari, Bryson, Streiner and Wilson, 2000). Some writers, however, suggest that this is over-stated, and that the adolescent period is not difficult for all young people on the autism spectrum (Wing, 1996, p162).

Hebron and Humphrey (2014) conducted a study in north Wales and north-west England, which compared the experiences of young people on the autism spectrum (N=22), to those with dyslexia (N=21) and to a control group with no additional needs (N=23). Their findings indicated that higher levels of anxiety, depression, anger and self-concept were experienced by the students with autism, in comparison to those with no additional needs, and higher levels of anxiety and anger when compared to students with dyslexia. Their mixed method approach meant that they were able to add important qualitative information in exploring the reasons for this. These included: difficulties with peer relationships, concerns around disrupted routines, and feelings of difference to their peers.

Their participants were recruited from seventeen mainstream schools and taking account of a wide range of variables within these different environments may make comparison between participants more challenging. This could be a limitation of the study. The reason for comparing autistic young people with those with dyslexia, a specific learning difficulty, is also not well explained. The findings, which reflect the relationship between anxiety and challenging social relationships, are supported in a range of other studies (Carrington and Graham, 2001; Portway and Johnson, 2003; Humphrey and Lewis, 2008).

Similar-aged participants took part in the study conducted by Acker, Knight and Knott (2018). Their participants reported an ongoing interaction between social communication

challenges and anxiety and described how difficulties in these areas highlighted their general differences, consequently leading to increased anxiety. A further finding in this study was that the young people did not seek external support with managing their anxiety. This may indicate that internalising unpalatable feelings may be a strategy used by some young people on the autism spectrum, and this was a finding that was also supported in the study by Hebron and Humphrey (2014). The recommendation of the authors, of a need to explore how to more effectively target support for these issues, is an important one.

2.5.3. *Identity*

Adolescence has been identified as a period of exploration and experimentation, and a time of questioning current identities. Erikson (1968) believed that the quest for 'identity' was a major personality achievement of adolescence and was an essential step in becoming a productive and content adult. Erikson expanded Freud's psychosexual framework (1905) and his psychosocial theory emphasizes the importance of social experiences in supporting personality development. A psychosocial conflict at each stage, which is resolved along a continuum from positive to negative, determines whether the outcomes will be healthy or maladaptive. For Erikson, adolescence included defining: who you are, your values and your future direction (Berk, 1997, p16). For young people on the autism spectrum, research indicates that there are often factors which may act as barriers or constraints within this process.

Some studies have demonstrated that young people with autism can have negative views of themselves, and that this may increase as they mature throughout their school years (Connor, 2000; Humphrey and Lewis, 2008; Hebron and Humphrey, 2014). In the study by Humphrey and Lewis (2008) the authors seek to explore how their participants constructed their identity, which included their perceptions of autism. All the participants were at mainstream secondary schools in North-West England. The researchers observed that many of their participants had negative perceptions of themselves. For example, they described themselves as 'having a bad brain' and as being 'retarded'.

These students felt that, within the school setting, there was a "constant negotiation of difference" (p 40). Although these students wanted to 'fit in', they reported that, on the

one hand, they were being treated differently to their peers by teaching staff, but in some areas they were expected to be the same as peers, for example in developing an increased level of independence. Within this environment, it was noted that in order to successfully negotiate the social world of the school, they had to adapt their behaviour to perceived 'normal' behaviour. In doing this, it was necessary to compromise their individual preferences which had a potential impact on their identity development.

Carrington and Graham (2001) supported these findings in their study with young adolescents in a mainstream environment, although their study may be limited by a very small sample size. They introduced the concept of "masquerading" in which their participants were seen to mask many of their feelings at school. The stress of hiding these feelings often led to emotional outbursts when they returned home. The researchers suggested that maintaining a 'normal façade' could lead to considerable stress and make them more vulnerable to mental health difficulties. This conclusion may be difficult to substantiate, but participants in other studies have indicated that an increase in stress levels caused by a range of factors within the school environment can lead to 'meltdowns' or emotional dysregulation (Acker et al, 2018), and this may support the general assertions of Carrington and Graham (2001).

Although these studies were concerned with some young people of lower secondary school age, similar themes have been identified in older teenagers (Carrington, Templeton and Papinczack, 2003) and in research with college populations (Bell, Devecchi, McGuckin and Shevlin, 2017).

In the study by Huws and Jones (2015) more positive findings related to identity exploration were identified. Huws and Jones (2015) explored the perception of autism for the participants in their study, nine young people diagnosed with autism, aged 16 years to 21 years. They interpreted their findings with regard to Social Comparison theory (Festinger, 1954) because although not directly asked, their participants compared themselves to other people with autism and other disabilities noting, for example, that others "had it really bad", and that their own difficulties were not as severe as other disabled people. For some of their participants, they reported that there had been an "attenuation in their autism traits over time" and that they felt that this was partly

because they had “grown up”. Others felt that they had become more socially aware over time and this had led to a sense of personal autonomy and independence.

These students however, attended a specialist college for young people with autism, so it is possible that within this environment they were not subject to the “constant negotiation of difference” that may be more prevalent within a mainstream environment (Humphrey and Lewis, 2008). Although these young people seemed to have developed a more positive view of themselves, it still seemed that this was related in some degree to ‘normalising’ their behaviour and that their awareness of a need to ‘fit in’ remained apparent.

2.5.4. *Fitting in*

‘Fitting in’ or gaining peer acceptance has been established as an important requirement for adolescents within a secondary school environment (Eccles and Roeser, 2011), and this has been related more widely to a sense of belonging within the school setting (Schall, Le Baron Wallace and Chhuon, 2016). An awareness of a need to ‘fit in’ with peers, and to conform to wider societal norms, but a more limited ability to effectively do so, has been a recognisable theme in research with young people with autism.

Differences in peer relationships and social difficulties are reported in many studies which explore the concept of friendship for adolescents on the autism spectrum (Carrington, Templeton and Papinczack, 2013; Acker et al, 2018). Carrington et al. (2003) reported a ‘lack of insight into what constitutes friendship’ in their participants and an inability to recognise their own social difficulties (p216). This is in apparent contrast to the accounts of the participants in the study by Acker et al. (2018) for whom, a very discomforting awareness of their social difficulties was a considerable source of anxiety for them. An increase in literature written by adults on the autism spectrum, reflecting on their earlier lives, adds further to our understanding, along with retrospective studies with adult populations (Portway and Johnson, 2003; Grandin, 2005; Muller, Schuler and Yates, 2008).

The young adult participants in a study by Portway and Johnson (2003) in the United Kingdom, expressed views that they “didn’t quite fit in”, and according to the researchers felt as though they were on the edge of society. They recalled that their school days had

become increasingly difficult as they grew older. They suggested that this was related to: “increasing social expectations from the child themselves as well as from peers, teachers, parents and society in general” (p438).

This retrospective study was focused on the experiences of growing up with Asperger Syndrome (AS). For the researchers the fact that they “looked normal” and “talked normal” (p442) meant that often their difficulties were missed by adults in school. It is proposed that during this period of schooling, a lack of understanding of the condition may have affected the response of adults within schools. Later studies, however, indicate that limited understanding of autism and low confidence in managing the needs of autistic children and young people may still be a factor for staff in educational provisions today (Jones, 2015; APPGA, 2017).

In common with other studies related to this population (Mitchell and Beresford, 2014) in the study by Portway and Johnson (2003) individuals with AS and their parents were interviewed, and in some cases joint interviews were conducted. In interpreting the findings in this study, it is possible that the presence of a parent may have had an influence on some of the views that were expressed by the young adults in the study.

Intense isolation was described as a defining feature of growing up with autism in a study by Muller et al. (2008). For their participants, the pain of this increased as they grew older and they became more conscious of being “different”, “alone” or “out of place”. One participant described feeling as if he was “at the bottom of a remote abyss, removed from everything, and not developing the normal peer relationships I perceived everybody else as experiencing” (p179). These individuals had learnt strategies to mask some of the difficulties that they experienced, as has been observed in other studies with adolescents (Carrington and Graham, 2001; Carrington et al, 2003).

The retrospective nature of these studies may have affected the accuracy of the recollections of the participants to some degree, but the findings are relatively consistent between individuals, and have been replicated in other personal accounts representing the views of adolescents (Jackson, 2002; Humphrey and Lewis, 2008).

The studies described have also largely concerned themselves with the smaller subset of individuals who have been diagnosed with Asperger’s Syndrome, rather than the broader

group of individuals diagnosed with autism spectrum disorder. It is possible that there could be a greater variation within the individual stories of this wider group.

2.5.5. *Independence*

One of the features of adolescence as identified in more general literature (Henderson et al, 2007) is the emphasis on the increasing independence of young people as they move through this period. This can mean a psychological and sometimes physical moving away from the influence of parents. Within the literature relating to young people on the autism spectrum, the relationship with parents and their position in the lives of their children does not seem to alter in the same way as with their non-autistic peers. Their role during school years (Mitchell and Beresford, 2014; DfE, 2014a) and within the period of post-sixteen transition remains a significant one (Held, Thoma and Thomas, 2004; Breakey, 2006; Camarena and Sarigiani, 2009). This may be reflected in research interest in eliciting the view of parents and professionals during this period (Eaves and Ho, 2009; Toor, Hanley and Hebron, 2016; Hatfield, Falkmer, Falkmer and Ciccarelli, 2017).

There may be a number of reasons for this continued involvement. As suggested in some literature, parents may be more involved in ensuring the suitability of educational provision for their children throughout the school years (Beresford, Tozer, Rabiee and Sloper, 2007; APPGA, 2017). Parental lack of confidence in the ability of settings to meet individual needs has also been noted in research, and this implies that some parents may continue to act as educators for staff and advocates for their children (Camarena and Sarigiani, 2009; Ambitious for Autism, 2011; APPGA, 2017).

Questions have been asked however, as to whether parents always completely understand the needs of their children (Garth and Aroni, 2003) and some researchers wonder if adolescents will choose to disclose all their concerns to a parent (Mitchell and Beresford, 2014). This implies that additional support in different settings will still be crucial.

Other studies also identify that many young people with ASD continue to rely on parents, often mothers, to provide practical as well as emotional support in later adolescence and into adulthood (Mitchell and Beresford, 2004; Howlin, 2012). A “blurring of life phases” as

described by Rydzewska (2012) however may add a further dimension to our understanding of this.

Within some studies, where parental aspirations are discussed, parents have expressed a desire for their child or young person to acquire independent living skills or 'real world' skills (Beresford et al, 2007; Tobias, 2009) and this appears to be in common with most other parents (Henderson, Holland, McGrellis, Sharpe, Thomson, 2007). The relationship between parental influence and its effects on the developing 'independence' of a young person with autism is a complex one which may need further exploration (Barrow, 2015).

2.5.6. Aspirations

Much of the research conducted in the area of adolescence and post-sixteen transition concerns itself with the difficulties and challenges that young people on the autism spectrum may face. It is essential, however, to recognise the positive features in the lives of these young people; in recognising their individual aspirations, and in promoting a greater sense of control or self-efficacy beliefs regarding their future (Sosnowy, Silverman and Shattuck, 2018).

A small body of research seeks to clarify if young people with autism have the same aspirations as their non-autistic peers. Camarena and Sarigiani (2009) report that young people with ASD have similar post-secondary educational hopes. Emancipatory projects such as 'We Can Dream' (The Foundation for People with Learning Disabilities, 2005) represent a person-centred approach to future planning and suggest that 'with the right support young people with autistic spectrum disorders can express creative ideas, dreams and hopes for their future' (p3). Autobiographical or small-scale studies have given us further information on individual aspirations (Jackson, 2002; Grandin, 2005).

Beresford et al. (2007) claimed that their study was "the first to explore desired outcomes for disabled children, including children with autistic spectrum disorders" (p14). It explored the views of parents and children, including twelve teenagers who were observed interacting in a focus group setting. The study demonstrated that the teenage participants "do hold and are able to express desires and aspirations" (p14) which were observed to be similar to their non-autistic peers. In acknowledgement of the broadness of the autism spectrum however, the researchers imply that the level of support required

to achieve these will vary considerably. In utilising a focus group format, it is possible however that group factors, such as deindividualization and greater compliance observed in some group situations, may need to be taken into account when interpreting these findings.

2.6. Literature: The pre-transition period.

2.6.1. *Disabling environments*

The previous section of this review has outlined some of the general features of adolescence and how these may relate to the experiences of young people on the autism spectrum, during this developmental period of their lives. For these young people a large proportion of this time is spent within an educational setting and it is proposed that the demands of this environment enhance and potentially create some of the difficulties that are experienced by a young person with autism (Oliver, 1990).

As Breakey (2006) explains:

If we listen to what autistic people tell us about autism, then one of the first things that we learn is... autism itself is not the problem. Their relationship with us and the environment is (p124).

In a study by Connor (2000) of young people with ASD, some of whom were in year 11, he found that:

even among students in mainstream schools whose autistic disorders are towards the mild end of the spectrum, the potential or actual difficulties should never be underestimated (p285).

Social difficulties were evident in the study by Connor (2000), as highlighted in many other studies, but his findings indicated that the concerns of the participants permeated all aspects of school life, including the learning environment. For example, most students showed a preference for school subjects that required less interaction with peers. Unstructured times such as breaktime and lunchtime periods could be a particular challenge for these students who often struggled to develop friendships with peers.

An observation made by a Special Educational Needs Coordinator involved in the study, was that in a one to one situation “behaviour, apparent confidence, and verbal expression may appear positive or ordinary” but was quite different and “definitely not seen as ordinary within a class setting” (p294). The exact features of this are not elaborated upon but other research suggests that concerns related to social misunderstandings and a level of social anxiety as a result of this, may be a factor in interpreting the behaviour of young people with ASD within a school environment (Hebron and Humphrey, 2014; Acker et al, 2018).

Bullying is also a theme often mentioned in research with this population. This could take the form of verbal or physical abuse or social exclusion (Humphrey and Lewis, 2008; Jackson, 2002). Some studies have suggested that because of a predisposition towards literal understandings that young people with autism can sometimes misinterpret humour or sarcasm and this can make them vulnerable to negative peer reactions (Jackson, 2002; Humphrey and Lewis, 2008). In a study by Beardon, Martin and Woolsey (2009), their participants rarely experienced empathy or understanding from peers.

In the study by Humphrey and Lewis (2008) the sensory demands in the school environment such as: crowded areas and noise were also a constant source of anxiety for their participants who experienced constant ‘stresses’ related to crowded areas and had difficulty concentrating in noisy environments. Sensory needs have now been included in the diagnostic criteria for ASD (APA, 2013) and for many on the autism spectrum are much broader than those reported in the study (Bogdashina, 2003; Baron-Cohen, 2008).

2.7. Literature: The transition period

2.7.1. The opportunities and challenges of the transition period

In this section, general issues that have been raised concerning transition will be discussed. For many young people post-sixteen transition can create new opportunities which includes moving into a new more adult environment and enjoying an increasing level of independence. It can also for the same young people introduce a level of risk in the form of uncertainty and unpredictability (Henderson et al, 2007; Siegel, 2013).

Specific features associated with the autism spectrum may create additional challenges for these young people during this period. It has been suggested that any type of change or transition can potentially be difficult for young people on the autism spectrum. Stoner, Angell, House and Bock (2007) propose that this can be both horizontal (transitions between daily tasks) and vertical transitions (changes between life stages). Unexpected changes in routine can also be problematic for some people on the autism spectrum (Rydzewska, 2016). Beardon (2017) believes that “many autistic people are not the slightest bit bothered by a lot of changes” (p48) but acknowledges that unplanned change can create more difficulties.

The preference for predictability and consistency (Wing, 1996) can mean that, by its nature, change can lead to an increase in anxiety. In post-sixteen transition, change for young people on the autism spectrum can often take the form of a physical change of environment as well as changes to the routines and structures of the day. The different social demands of this environment can also offer new challenges (Adreon and Durocher, 2007). It has been suggested that more reluctance to engage in new experiences can make young people with autism, less likely to engage in career planning and their approach to making choices in general, means that any careers support needs to be tailored to meet their needs (Mynatt, Gibbons and Hughes, 2014). Although this is based on a fictional ‘case illustration’ which may undermine its applicability to some degree, the value of targeted advice based on the unique needs of the individual is a sensible conclusion.

For Rydzewska (2012) the variety and unpredictability of pathways after leaving school may increase vulnerability for young people on the autism spectrum who may struggle with choice and decision-making, as a result of probable executive functioning difficulties (Baron-Cohen, 2008).

In a comparative study by Browning, Osborne and Reed (2009) the researchers concluded that transition is experienced differently by young people on the autism spectrum and it can be a time of increased stress. In their study, Browning et al. (2009) compared perceived stress and coping in adolescents with and without Autism Spectrum Disorders (ASD) in the United Kingdom, as they approached leaving school. Their findings indicated that young people with ASD worried more than their peers at this time and that their

concerns were different. They worried less about the potential academic pressures, as expressed by their neurotypical peers, and more about practical concerns such as, using public transport.

As supported by other research (Bell et al, 2017) concerns about forming social relationships in a new provision were also expressed by participants and this was predicted by difficulties that they had experienced in this area previously. Their participants also suggested that they internalised stress; were less likely to seek support from others and believed that stress would be an ongoing problem for them. In comparison, participants without ASD had more recognisable strategies to manage stress and felt more able to cope with this.

In the study by Browning et al. (2009) the researchers concluded that this may indicate that these young people had not had access to appropriate support to manage their needs in the past or had not directly sought it. The findings in the study by Hebron and Humphrey (2014) and Acker et al. (2018) may support the view that young people with autism may be reluctant to seek support. Other studies indicate however that the personal qualities of supporting individuals are crucial and that young people with autism may share more of their thoughts and feelings in relationships where trust has developed (Bell et al, 2017; Mitchell and Beresford, 2014). In interpreting the findings in the study by Browning et al. (2009) an interview length of only 5-10 minutes, could be a limiting factor in that it may not have been possible for the participants to provide detailed information or develop any sense of trust within this timescale.

2.7.2. The process of transition – views from young people

The necessity of effective support for young people and their families during post-sixteen transition has been highlighted in a range of literature and reinforced by government guidelines and policies (DfE, 2002; DfE, 2015a). The importance of listening to the voices of young people has been endorsed by societal changes (Article 12, UNCRC, 1989) and advocated strongly in more recent regulations (DfE, 2015a). There have however been limited empirical studies that include the direct views of young people with additional needs in this area (Preece and Jordan, 2009).

An important study was conducted by Mitchell and Beresford (2014) concerning the transition experiences of young people with autism. Their sample included young people between the ages of 15 and 21 years old with high-functioning autism or Asperger's Syndrome and included participants on the cusp of leaving school, as well as those with recent experiences of further education.

In their study it was reported that their participants welcomed the involvement of practitioners, and specific forms of help, such as careers support. However, the lack of an appropriate person to co-ordinate the transition process was conspicuous. There was little evidence of effective transition pathways being implemented in preparation for the next educational provision of their participants. They claimed that they were not aware of any formal planned transition processes, although one young person had received 'travel training' to support him with catching the bus. For these young people, parents were most often recognised as the most significant and valued sources of support in both a practical and emotional sense.

Amongst the eighteen participants, no targeted support was offered to prepare them for life in a further education setting. Concerns relating to the social demands of the further education environment were often stated by the participants but none of them had been offered or received social skills support from a practitioner.

The findings reported were part of a larger study on transition and it was confirmed that the experiences of young people were similar in different parts of the country and local policies did not seem to make a difference. In this study, the participants were self-selecting and at different stages of the transition process which may make direct comparison between accounts less effective. Their lack of awareness of the transition process, however, indicates that, regardless of their stage of transition, there was little evidence of their views being considered, in apparent disregard of the importance of this. This study seems to display that there were significant gaps in the transition process for these young people at this time and similar experiences have been described by participants in later research (Bell et al, 2017).

A more recent study by Bell et al. (2017) explored the process of transition as experienced by students with ASD in the Republic of Ireland as they moved onto further education

college or higher education. They divided their study into pre and post transition phases to capture aspects of both periods. The purpose of the study was to identify the resources and supports which were in place during this time as well as identifying any issues or barriers. Their age range was clearly defined and involved six young people aged between 17 and 19 years.

Their findings were similar to those of Mitchell and Beresford (2014) and there was little evidence that transition planning had been initiated as a formal process for any of their participants. In the pre-transition phase, they also identified that positive relationships with school staff were valued, as well as the practical support of professionals, such as Career guidance professionals.

For some of the participants in this study, anxiety was a defining feature throughout this process. One of the concerns expressed was around the anticipation of leaving behind the support of important personal relationships built up with key professionals over time and anticipating that this may not be available in the next provision. One participant explained that “I’ll be trapped in myself again” (p64) perhaps expressing his difficulty with sharing his feelings other than with trusted adults. For other participants there was also an acknowledgement that the transition period was part of maturing and moving onto adult life and they approached it with cautious optimism.

In their study, Bell et al. (2017) identified that young people with ASD had very specific needs that were not being addressed (p63). They concluded that “nuanced and sensitive responses from policy-makers and practitioners” (p66) were required to meet the needs of this group during this period of transition. A request that has been visible throughout the research concerning this period (Chown and Beavan, 2012).

A strength of this two-part study is that it attempts to provide an extended view of transition. The post-transition interview took place within a few months of transition however and although it was acknowledged that all the students seemed settled in their new provision at this time, it was difficult to assume that this would naturally continue. In support of the approach, it is also possible that if the participants had some negative experiences, they may be more willing to disclose these to a researcher who they had

met previously. A longer-term study may give us a greater understanding of how experiences may be mediated over time.

Shepherd (2015) explores transition using a longitudinal case study approach with six participants with autism over a ten-month period, which covered their preparations for leaving a specialist secondary provision and for six months in their new college setting. Her article relates to the experience of one participant as she examines the effectiveness of using a combination of participatory methods in order to fully engage the participant in the research process. These include: Visual methods, tablet applications and walking interviews. The methods used all seemed to have some value in allowing the participant to share his story, which was a largely positive story of hope and optimism. Finding appropriate methods to seek the voices of young people with complex needs, is an area that shows some signs of developing in research with adolescents on the autism spectrum (Hill, 2014). A case study approach, however, may limit its more general applicability.

Toor, Hanley and Hebron (2016) offer a review of qualitative literature in this area which aims to identify facilitating factors and obstacles for young people transitioning to and accessing further and higher education. Their review of twelve studies supports themes that have been noted in other research such as: the value of support from professionals; the need for the process to be co-ordinated; and the value of approaches which are personalised to support individual needs.

Their review has similar constraints to some other studies in that there is a greater focus on the experiences of young people entering higher education and the majority of the reviewed studies were small scale, of less than ten participants. The studies reflected an international context and half were from countries other than the United Kingdom. Not all of the studies included student views, information being gathered from members of staff or parents and this is a pattern observed in other research (Hatfield et al, 2017). The review contributes to a picture of the type of support that is valued by individuals but with only one study directly relating to the experience of young people in further education (Mitchell and Beresford, 2014) it adds only limited information to the general evidence base of research in the United Kingdom.

2.7.3. *The process of transition – an international context*

As stated previously the literature from other parts of the world in this topic area has been more abundant than in the United Kingdom (Roberts, 2010). In attempting to provide a shared understanding of the processes involved, Roberts (2010) describes the features of transition-planning in the United States:

Transition-planning is a process or *co-ordinated set of activities* designed to successfully move students...from school to post-high-school settings (p158).

The importance of co-ordination is apparent in this definition but within a country where the process has been established for a longer period (IDEA, 2004) there is still extensive debate related to the shortcomings in the process. In the view of many, it is failing to meet the needs of young people with autism or supporting them to achieve better outcomes when they leave compulsory education (VanBergeijk, Klin and Volkmar, 2008; Hendricks and Wehman, 2009).

The review by Hendricks and Wehman (2009) focuses on research related to transition for young people on the autism spectrum from school to adulthood in the wider areas of transition to education, employment and community integration. In common with most research in this area, they suggest that students with autism do not form a heterogenous group and individually tailored plans are required.

They also note that research indicates that only a third of young people are present in their transition meetings and only 3% are involved in leading their meeting. The reasons for this are largely unclear but Hendricks and Wehman (2009) suggest that this is a “pivotal component of planning that has been greatly overlooked” (p83). A further conclusion is that this process should take place over a much longer time period, beginning in primary school, and continuing more intensively when students are in later secondary years, in agreement with other research (Baric, Hemmingsson, Hellberg and Kjellberg, 2017; Held et al, 2004).

The elements which should be focused on in a more drawn out process are not clearly defined. Within their review, the transition period is also not clearly stated, and they describe that the majority of their participants in the studies that they reviewed were

over 13 years old but there was no information on the upper limit of ages involved. Although there may be similarities, the experience of a young teenager may be quite different at this stage of a transition journey, to that of an older teenager preparing for an imminent move to college.

Within the literature, there is a general agreement that the most appropriate methods to use in transition-planning are those that are personalised or 'person-centred' as supported by literature and legislation within the United Kingdom (Breakey, 2006; DfE, 2015a; White and Rae, 2016).

A study by Held, Thoma and Thomas (2004) describes a person-centred transition process for a young man with autism in the United States. Their action-research project focuses on the experience of John Jones over a period of at least a year. In this process, it was felt that the perceptions of people around John began to change as more control was passed over to him with regard to his future-planning. Over time, he was observed as being more competent and, in the view of the authors, further self-determination and self-efficacy beliefs were promoted by this.

There is little to argue against this approach, but it is evident that a significant commitment of time and energy was needed by others around John to enable this to take place. A case study approach also means that findings from the study are difficult to generalise. The authors also recognise the importance of more longitudinal studies that focus on the entire process of transition-planning, to further explore the processes involved.

For Hatfield, Ciccarelli, Falkmer and Falkmer (2018) when transition-planning is 'done well' it can lead to greater self-determination in young people with autism, and this they believe, is supported in a study by Hagner, May, Kurtz and Cloutier (2014).

In the study by Hagner et al. (2014), the authors identified strategies and supports to help young people with ASD to be more involved in the transition process. Successful examples of these being implemented were included in the study. These covered: Individualized preparation for meetings, informal activities to build rapport between the facilitator and the youth, flexible meeting designs, distance attendance and support for alternative means of communication. Within this study, as identified by Hatfield et al.

(2018), it is evident that for the researchers the 'person-centred' element extended well beyond the parameters of the meeting. The researchers however recount the aims of the study as "a descriptive study" to be "viewed as only a preliminary investigation" (p9). Descriptive studies are more typical of research in this topic area (VanBergeijk, et al, 2008) and suggest that the processes which support involvement require additional exploration.

Hatfield et al. (2018) in their study gathered the views of young people and parents through an online survey. Their findings, as identified in other studies (Roberts, 2010; Mitchell and Beresford, 2014) led to the proposal that factors that relate to "successful transition planning" included "a clear plan with a coordinated approach, scheduled meetings and clear formal documentation" (p3). The study is important however in recognising that a range of factors will have an influence on the success of the process and these, they defined as:

- Pre-disposing factors, which they described as cognitive factors such as self-efficacy.
- Reinforcing factors, which included strategies to reward continuing engagement.
- Enabling factors, such as the environmental conditions, within the process, including a clear and co-ordinated plan and approach.

They also acknowledged that "autism-specific" factors impacted on these areas. For example, anxiety, motivation, insight and choice, will influence the process and it is necessary to consider these, in maximising the effectiveness of the process. This study offers a comprehensive assessment of a range of factors which require attention in the transition process, and this gives it some practical value but also indicate the complexities involved. The possibility of collusion in assessing the views of both parents and young people in the same study should be considered in interpreting the more general findings.

2.8. Literature: Post-transition period

2.8.1. *Life in further education*

In this section, I will consider the period following transition and explore research which examines the possible opportunities and challenges that further education may introduce for young people on the autism spectrum.

The literature which involves young people predicting life within a further education environment seems to intimate that they have restricted knowledge of this (Browning et al, 2009) and any concerns that they have, are often related to past experiences (Mitchell and Beresford, 2014; Bell et al, 2017). There is a worry that this may indicate that young people with autism lack a good understanding of the opportunities and challenges of life at further education college and this may be connected to limited information and poor transition-planning (Mitchell and Beresford, 2014; Ofsted, 2016; Bell et al, 2017). More general literature maintains that there will be noticeable differences within a further education environment (Breakey, 2006; OECD, 2011)

Within a further education environment, the range of courses that young people may engage in will be broader. Some students will be enrolled in full-time vocational courses whilst others may continue a more academic pathway (Breakey, 2006). Particular concerns have been expressed around foundation learning programmes in meeting the needs of autistic learners (Ambitious for Autism, 2011; Ofsted, 2016) and general limitations regarding the range of learning programmes (Wolf, 2011), but there is a little research which examines the specific challenges that may be present within different courses (Beardon et al, 2009; Bell et al, 2017).

Some writers predict that the characteristics associated with autism mean that these young people may encounter more difficulties within a further education environment. For example, delays in the speed of processing information and executive function difficulties may have an impact on their ability to understand, plan and organise academic work (Adreon and Durocher, 2007). More studies have considered the different levels of academic and social demands at both college and university within the same study where the range of courses are much larger, but this may fail to appreciate the differences between further and higher education courses (Cai and Richdale, 2016). In common with

literature in the wider area of post-sixteen transition, the 'voice' of the young person has been neglected but dedicated individuals are attempting to address this (Beardon, 2017).

Chown and Beavan (2012) suggest that much more attention needs to be paid to the teaching process, not just the qualification at the end. They draw from work on higher education models of student support, as in many cases, they believe that these are as applicable to colleges as they are to universities. They suggest in their review of literature and research relating to autism in further education, that a "one size fits all" approach will not work and that support needs to include: individual profiling of the ability of each autistic student, their potential learning style, their use of verbal and non-verbal communication, any sensory processing difficulties, social skills, specific talents, anxiety levels and potential triggers for anxiety. The breadth of these needs is evident with a significant financial outlay required, but the authors do not offer any clear advice on how this could be managed.

For Bell et al. (2017) the social demands that are implicit in the curriculum, such as increased group participation within classes and flexible assessment processes within colleges have not been sufficiently acknowledged and could be a source of anxiety for some young people on the spectrum. Different sensory issues were also acknowledged as potential barriers within this environment, as well as the difficulties presented to these students by a generally less structured environment (Cai and Richdale, 2016).

The numbers of young people with autism who are now at further education college has been steadily increasing (DfE, 2018a) but much of the literature indicates that limited knowledge and understanding of autism amongst many educational professionals persists within this environment (Breakey, 2006; Beardon et al, 2009; Chown and Beavan, 2012; APPGA, 2017).

The link between "knowledgeable support" and "improved prognosis" (Chown and Beavan, 2012, p477) is one that has been established in a wide range of literature (Ambitious for Autism, 2011; APPGA, 2017; AET, 2018a) but the relationship between successful outcomes and the exact nature and amount of support required, has been less easily defined.

It seems evident that there will be differences in the opportunities and challenges within a further education environment when compared to secondary school. To a large degree due to a limited amount of research which takes account of the broadness of the autism spectrum and the individual differences of individuals within it, it is difficult to predict what these challenges may be. Further qualitative research seems essential in this area to gain a better understanding (Chown and Beavan, 2012; Beardon et al, 2009).

One approach that has been advocated to support young people with autism during this transitional period is an Ecological approach (Toor et al, 2016; Dente and Parkinson-Coles, 2012). Bronfenbrenner and Ceci's bio-ecological systems theory (1994) offers a systemic approach which can help to understand and define the potential areas of need.

The theory acknowledges that it is important to study the child or young person nested within a system of multiple environments. These are: Microsystem (immediate environment, which would include home and school), Mesosystem (interaction between the different systems), Exosystem (systems indirectly related to the child, but still influential), Macrosystem (distant people and places, cultural patterns and values) and the Chronosystem (change and consistency within the child's environment). For Bronfenbrenner and Ceci (1994), it is important to understand the bi-directional influences that exist within these systems, in considering the experience of any individual within society. Features unique to the individual also have a bearing, including biological, cognitive and emotional factors.

2.9. Specific challenges for young people with ASD during the period of post-sixteen transition

This literature review suggests that some of the challenges which face young people with ASD during the post-sixteen transition period are similar in nature to those experienced by many adolescents approaching this time. This includes feelings related to the uncertainties within the further education environment, and this may concern relationships with both peers and further education staff, as well as the specific requirements and demands of new courses. For all young people this may be balanced, to some degree, by feelings of optimism relating to more general aspirations associated with this period (Henderson et al, 2007; Bell et al, 2017). It is argued that the timing of post-

sixteen transition within adolescence can create additional challenges for all young people associated with identity exploration and developing independence (Erikson, 1968; Siegel, 2013). The literature also indicates however, that there are some very specific challenges for young people on the autism spectrum during this time and these can be summarised as follows:

- Young people with ASD often experience higher rates of anxiety during this period, in comparison to their neurotypical peers (Browning et al, 2009; Hebron and Humphrey, 2014). They may approach transition with more caution than a ‘typically’ developing adolescent (Portway and Johnson, 2003; Bell et al, 2017).
- Features associated with the autistic condition, namely differences in: Social communication, social interaction and ‘restricted and repetitive patterns of behaviour, activities or interests (including sensory behaviour)’ (APA, 2013) may become more evident in the further education environment where social and communication demands are often greater, and the sensory environment can be more complex (Chown and Beavan, 2012).
- There is a greater expectation during this time that young people will be moving away from physical and emotional dependence on parents and towards greater independence and have achieved a degree of social competence related to this. This may not always be the experience for young people on the autism spectrum (Mitchell and Beresford, 2014; Huws and Jones, 2015).
- Young people with ASD may have developed negative self-perceptions (Humphrey and Lewis, 2008), sometimes due to social comparison processes (Huws and Jones, 2015) or recent experiences. It is possible that this will continue to have an impact on their experience as they move through post-sixteen transition.

2.10. Conclusion and research aims

This literature review has focused on the issues that affect young people with ASD through the different stages of post-sixteen transition. It has also considered factors that may be beneficial for an effective transition for this population. The literature indicates that although there is an extensive body of work around the transition processes for young people with autism in the United States of America there is a notable lack of

research from the United Kingdom. Research which considers the process over an extended time period is also very limited.

Although research in this area is vast, it is important to highlight some of its limitations. Many studies offer a review of research in this area, but the scope and detail of the studies reviewed, as well as evidence of 'autistic voices', is sometimes unclear. The study by Rydzewska (2016), is an example of this and, along with other studies on this population, it has a regional flavour, with specific local services being mentioned. This may limit its more general applicability. Other studies focus on small numbers of individuals often with complex needs, such as the studies by Shepherd (2015) and Held et al. (2004) and although these have value in identifying the experience of individuals, the uniqueness of the cases, may make comparison between studies, significantly challenging. Other writers are also well-known advocates for the rights of autistic people and their position is clearly identified. In the study by Beardon et al. (2009), a noticeable degree of disdain for the behaviour of 'neurotypicals' is described and although I have sympathy with these views, it may suggest that some caution is advisable in interpreting the findings of the study.

Having considered the literature in the area of post-sixteen transition, there appeared to be considerable gaps in the research available.

From this, the aim of the current study was to identify and explore the lived experience of the transition process for young people on the autism spectrum. I was keen to learn more about the thoughts and feelings of young people as they left year 11 and began a further education course. I was also interested to explore transition processes that were in place. In this research, it was important to capture the voice of the young person throughout the transition process as I believe that this has been neglected.

Two broad research aims developed in response to this:

- To explore the participants' unique experience of post-sixteen transition.
- To identify if there were any factors that had a particularly positive or negative effect on their experience.

Chapter 3

Methodology

3.1 Chapter overview

In the previous chapter I reviewed the literature which related to the current research. The review identified that although there has been an increase in research which included the voices of young people with autism, this is still very limited. There is a distinct lack of research that is related to the experiences of young people with autism during the period of post-sixteen transition and particularly that which originates from the United Kingdom where the process and timing of transition may be different to many other countries. In relating to my own personal and professional experiences of young people with ASD, it was essential to me that this was addressed, within my study. In reviewing the literature, it was also apparent that some negative perceptions existed around the possible limitations of young people with autism (Huws and Jones, 2010). It was important to me that these were challenged and that exploring the 'lived experience' of these young people would offer a more holistic understanding of their lives.

This led to two broad research aims for my study:

- To explore the participants' experience of post-sixteen transition.
- To identify if there were factors that had a particularly positive or negative effect on their individual experiences.

This chapter aims to:

- Provide a rationale for choosing a qualitative research approach whilst also considering my position with regards to epistemology and ontology.
- Outline the theoretical underpinnings and characteristics of IPA and the reasons for choosing an IPA methodology.
- Discuss the research design and the processes undertaken as well as explaining the reasons for my choices.
- Offer a brief exploration of the debates around the specific role of language in qualitative research.
- Explore the ethical considerations in this research study.

This chapter draws on previous papers submitted for part completion of my Doctorate in Educational Psychology (Chavez, 2017).

3.2. Choosing a qualitative research approach

In choosing a qualitative research approach, there were a number of considerations to take into account. I believe that a qualitative method offered the most appropriate approach for my study as qualitative approaches aim to explore how people view the world around them (Kvale, 2007) and this complemented my research aims. I was interested to explore the subjective experience of post-sixteen transition as perceived by young people with autism and the individual differences between them. This is in contrast to a positivist paradigm which supports the idea that there is a level of objectivity within the world which we can identify. As described by Willig (2013, p4) 'positivists believe that it is possible to describe what is 'out there' and to get it right'. In my view, this is an unrealistic aim because I believe that there are many different versions of the same reality and that individuals will 'construct' their own version, which is more consistent with a constructivist paradigm.

I would propose that in focusing my research on young people with autism, that there may be additional factors to consider. Personal accounts, which have been written by individuals with a diagnosed autism spectrum condition (Grandin, 2005; Milton, 2014) describe how they experience the world in a qualitatively different way to non-autistic people. A further consideration within this study was my interest in observing individual differences between my participants whilst acknowledging that there was likely to be some common ground between them. In my view this could only be truly achieved through using a qualitative approach in which individuals are able to express their views.

In the current study it was particularly important that the voices of the participants, as young people, were heard. There has been increasing recognition over time of the rights of children to express their views (UNCRC, 1989) but the research community have been slower to respond to include the voices of children and young people with a range of additional needs (Watson, Abbott and Townsley, 2006). Studies with children and young people with ASD, in an attempt to triangulate information, often include the voices of parents and professionals (Beresford, Tozer, Rabiee and Sloper, 2004). It is possible, in these situations, that the voice of the young person can be overshadowed by more 'powerful' voices.

Research indicates that parents continue to play a significant role in supporting young people with autism with their practical as well as their emotional needs (Howlin, 2005; Mitchell and Beresford, 2014). The continuing role of parents during post-sixteen transition may imply that they remain influential in the lives of their offspring (Breakey, 2006). It was therefore important to me that the views of others, such as parents or professionals, did not dominate and this led to the decision to focus solely on the voices of young people within my study.

There is a limited body of research which specifically captures the views of young people with autism (Preece and Jordan, 2009). Diagnostic assumptions may impact negatively on decisions about whether to include young people with autism in research and there have been concerns about vulnerability and exploitation which may have had an impact on their inclusion (Lewis, 2009). However, researchers who have engaged in research with this population have often been surprised by how positively some of these young people have engaged (Beresford et al, 2004).

The study by Beresford et al. (2004) focused on identifying the best method to explore the social care experiences of young people with ASD. In their study, the researchers ensured that they tailored their methods to the needs and abilities of their participants. They recognised however, to some degree, that they had under-estimated the willingness of some of their participants to engage and that 'there was a strong sense that, had it been possible, a repeat visit(s) would have allowed further exploration with the children about their lives' (p184). They also suggested that the parents were surprised by their children's engagement in the research process. In some cases, their own assumptions were challenged. They had previously believed, for example, that children with ASD could only understand concepts that were concrete and immediate but discovered that some of the children were able to respond appropriately to more abstract questions concerning their likes and dislikes. These findings were encouraging when planning my research.

3.3. Choice of methodology

I will now explain further my choice of IPA as a methodological approach. One of my reasons for this choice was because I wanted to maintain the voice of the individual whilst observing similarities or themes between theirs and the accounts of others. For me this

felt respectful of the stories that they told. My commitment to ensuring that the voice of the young person is heard and that their lived experience is sought meant that I explored a number of different approaches to data collection. I briefly considered using grounded theory (Charmaz, 2006) because it is a well-established and rigorous method of data analysis that shares many features with IPA (Willig, 2013). The differences, however, make IPA more consistent with my epistemological approach. According to Smith et al (2009, p202) grounded theory aims to 'identify and explicate contextualized social processes that *account for* phenomena, whereas IPA is interested in the *nature or essence of phenomena*'. My focus, as an independent researcher in attempting to understand the 'lived experience' of young people with autism, meant that I was very interested in the detail of their lives and how they personally experienced it. In my opinion, this would be more effective with a small sample size. Grounded theory often concerns itself with larger sample sizes (Charmaz, 2006).

I also contemplated a narrative approach which also has a strong intellectual connection with IPA. Both IPA and narrative approaches have an idiographic focus and roots within a phenomenological epistemology. Narrative approaches are more concerned with maintaining participants' original narrative and take a more descriptive phenomenological approach (Smith, 2003). One of my main concerns with a narrative approach to interviewing, however, was that it might have proved to be more challenging for the participants. Providing them with a planned loose structure for the interview through a topic guide, could support them more effectively, if they experienced anxieties related to uncertainties within the interview. Anxiety created by unpredictability can be a feature of the experience of individuals with autism (Baron-Cohen, 2008).

On a practical level, IPA also offers a comprehensive approach to qualitative research in that it specifies guiding theoretical principles, as well as ideas for research questions and study designs. It also suggests appropriate methods clear processes for data analysis (Braun and Clarke, 2013). For a novice researcher like myself, detailed guidance particularly around analytical procedures seemed to be an advantage (Smith et al, 2009).

In an attempt to explain the appeal of IPA, I believe that it is also important to understand its constituent parts – Interpretation, Phenomenology and Analysis and the unique role

that the researcher plays within this. The approach is recognised by the combination of these different parts (Chavez, 2017).

3.3.1. Phenomenology

The hope of phenomenological research, according to Willig (2013, p16) is 'to capture something that exists in the world'. Examples of this would be the thoughts, feelings and perceptions of research participants. For Smith (2004) it is the 'quality and texture' of the experience that is of interest to phenomenological researchers.

IPA is a version of the phenomenological method that agrees that it is impossible to gain direct experience of the research participants' world. It stresses the importance of the researcher and proposes that the researcher's view of the world, and the interaction between the researcher and participant, means that any phenomenological analysis is an interpretation of the research participant's experience (Smith et al, 2009). This is consistent with Heidegger's hermeneutic phenomenology which places an emphasis on understanding and making sense of a person's experience, rather than just describing it.

For Larkin et al (2006):

Our success as a phenomenologist will be dependent upon our being prepared to do the most sensitive and responsive job we can (p108).

This emphasis stresses the responsibility of the researcher and confirms that personal qualities are important. This appealed to my commitment to this research area and my intention to be fully and sensitively engaged in the research.

3.3.2. Interpretation

In contrast to 'descriptive' phenomenologists, 'interpretative' phenomenologists believe that it is not possible to produce a purely descriptive account of someone's experience and that there is always a level of interpretation within this (Willig, 2013, p17). Smith (2011) explains that for the empirical researcher, experience requires a process of engagement and interpretation on their part and that this is related to a hermeneutic perspective (p10). Smith (2011) describes the researcher in IPA as engaging in a 'double hermeneutic', as the researcher 'trying to make sense of the participant trying to make sense of what is happening to them' (p10). A certain flexibility in the approach is also

appealing in that we cannot predict, prior to data collection, the type of data that will be collected. This is expressed as follows:

..... a range of strategies may be used at the interpretative stage of IPA...The strategies chosen will depend upon the commitments and interests of the researcher, the research question in hand and the more general requirement for a coherent analysis (Larkin et al, 2006, p116)

It is proposed by Smith (2004) that IPA recognises that the researcher can engage in different levels of interpretation. As noted previously, for novice researchers it is felt to be a popular approach because of the systematic nature of the procedures involved in analysis. Some have suggested, however, that novice researchers may be too 'cautious' with their levels of interpretation (Smith et al, 2009). Being aware of this, as observed in the later chapters, I have attempted to avoid this within my interpretation of the participants' accounts.

3.3.3. Analysis

The third major influence on IPA is idiography. This is concerned with the particular and is observed in IPA's sense of detail or depth of analysis. This is required in order to understand how a particular 'experiential phenomena have been understood from the perspective of particular people, in a particular context' (Smith et al, 2009, p29)

Smith et al. (2009) offer a detailed description of the process of analysis within IPA. It has been described as an 'iterative and inductive cycle' (Smith, 2004, p43) which, according to Smith et al. (2009) proceeds by drawing on a range of strategies which I will describe later in this chapter. The culmination of this process should be the organisation of the material in a format which 'allows for analysed data to be traced right through the process, from initial comments on the transcript, through initial clustering and thematic development, into the final structure of themes' (Smith et al, 2009, p80).

The understanding of the intellectual tradition of hermeneutics and the hermeneutic circle is an important element of IPA. Although Smith et al. (2009) describe a linear approach to conducting an IPA study, the process of analysis is fundamentally an iterative process, moving back and forth through the process, and according to Smith et al. (2009),

it may help 'to think of one's relationship to the data as shifting according to the hermeneutic circle, too' (p28). Reflecting on my 'relationship' with the data throughout the process, I can relate my experience to this description and the 'shifts' that took place within my thinking.

3.4. The Research Design

3.4.1. *Participants - Selecting a sample*

In order to fulfil the aims of my study, I was interested in recruiting a purposive sample and have included details of the inclusion criteria in Appendix 2.

It is possible in IPA studies to use smaller numbers of participants so that the individual experience is captured whilst being able to note the convergence and divergence across participants (Brocki & Weardon, 2006). Smith et al. (2009) suggest that between four and ten interviews are the optimum number for a professional doctorate. With this in mind, I was hoping to recruit between four and six participants. The plan was to speak to them on two separate occasions, the first time when they were in year 11 and again when they were in year 12.

3.4.2. *Initial stages of recruitment and informed consent*

My participants were mainly recruited between March and May 2017. I initially e-mailed all Educational Psychologists within the local authority to give them details of my study and ask if they were aware of any schools or individual students who might be interested in taking part in my research. At the initial planning stages of my thesis topic, my main interest was to explore the experiences of young people who were educated within a mainstream environment. However, the restricted time frame, which quickly became apparent, meant that I decided to recruit more widely to include individuals in more specialist provisions such as resource bases attached to mainstream schools and schools which catered for individuals with social and communication needs. I decided that this may prove to be an advantage, in noting any differences in the transition processes in various settings and how this was experienced by the young people.

My initial request led to the identification of key contacts in schools and resource-based provisions within the county but not to any individual participants. The process then continued as outlined:

- I e-mailed the Special Educational Needs Coordinators (SENCo) within the counties' secondary schools in order to outline my research and ask if they were any potential participants in the setting.
- If a response was received, I then arranged a date to visit the school to discuss the research further with the SENCo. I was able to check the appropriateness of the content and layout of information sheets prepared for possible recruits, which led to some amendments.
- I then e-mailed pre-visit information sheets to SENCos. This included: an information sheet for potential recruits (see Appendix 3), an information sheet for parents (see Appendix 4) and one prepared for the Head teacher, outlining the research and asking them for consent to conduct research within the school (see Appendix 5). If interested students were identified, I arranged a date to visit the students.
- I met with the students in school and discussed the research with them, either individually or within small groups. I explained the structure through showing them a topic guide. There was also an opportunity for them to ask any questions and clarify information. I left them with a more detailed information sheet and consent sheet (see Appendix 6). Information sheets were also prepared for parents which the students took home. Parental consent sheets were also included for students under the age of sixteen (see Appendix 7).
- I spoke to the SENCo in the following week to confirm if any students were interested in taking part.

3.4.3. *Further considerations in recruitment*

From my past experience, I was aware that a lack of clarity around processes and expectations could increase levels of anxiety for young people on the autism spectrum. In order to address this, I ensured that processes relating to the research were as transparent as possible and I provided resources to support this. For example, I provided

a picture of myself on the information sheets and a topic guide (see Appendix 8) so that they could familiarise themselves prior to my visit.

I had also read a number of research papers which assessed the use of different resources in research with young people on the autism spectrum and I took some of their findings into account (Harrington, Foster, Rodger and Ashburner, 2013; Shepherd, 2015). Their findings suggested that providing information in a 'social story' style format (Gray, 2015) which described the study concisely and was represented visually, was an effective way for young people on the autism spectrum to access information.

In considering the recruitment of my participants, I was also mindful of the fact that they were in year 11 and that interviews would need to take place outside of the GCSE exam period. I clearly conveyed this in written and verbal information. This did mean however, that I had a limited time frame in which to recruit and conduct interviews. I believe that these restrictions and the demands of the exam period had an effect on some difficulties with recruitment.

3.4.4. *Recruiting a sample*

Over the recruitment period, I was able to recruit four male participants from four different schools.

Table 1 – Details of the participants in the study

Name (pseudonym)	Educational provision (Year 11)	Original diagnosis	Educational provision (Year 12)
Jack	Average-sized mainstream Academy (secondary)	Autism and learning difficulties	Mainstream further education college
Tom	Resource-based provision (in a separate building but close to a mainstream secondary school)	Asperger's Syndrome	Mainstream further education college
Adam	Independent school for children and young people with social and communication difficulties	Asperger's Syndrome	Mainstream further education college (One day each week at independent school to re-take GCSE English)
Matt	'All-through' Academy (Incorporating primary and secondary students)	Atypical autism	Place offered at mainstream further education college

Each of the schools were within the same county but were geographically quite far from each other. All schools were co-educational.

All the participants had received a statement of special educational needs in the past. I chose not to review these because my research focus was on the experience of these individuals rather than what support needs were identified in this document. It is acknowledged however that this may have had an impact on the type and amount of support that was available to them.

On leaving year 11, the participants who continued in the study were enrolled in a course at a mainstream further education college. They all attended different further education colleges, the geographical areas in which the participants lived had an influence on their initial choice of college.

3.4.5. *Anonymity and confidentiality*

It was explained to all participants that the results of the research would be published in my research dissertation. Participants were asked to choose a pseudonym so that their information was anonymised.

3.5. Research Processes

3.5.1. *Choice of Method*

Semi-structured interviews are advocated as an effective method to use within an IPA study and allow participants to share their voice:

an opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length (Smith et al., 2009, p.56).

As outlined by Smith and Osborn (2008), IPA has a theoretical commitment to the person 'as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people's talk and their thinking and emotional state' (p52). They recognise however that this 'chain of connection' is complicated and reasons for this may be that some people may struggle to explain what they are feeling or thinking, or they may not wish to share this with a researcher. It is then for the researcher and participant to make sense of this.

In support of Willig's (2013) view I was mindful that semi-structured interviews, more than any other type of interview are dependent on rapport established between the interviewer and the interviewee. It was important therefore to ensure, as much as possible, that I was able to use my skills in relationship-building and had sufficient time to develop a good level of rapport with participants. For Willig (2013) there is also an ethical dimension in that, an ambience created within the interview may lead to the interviewee revealing more than they are comfortable with during the interview. For Smith et al (2009) this rapport and ambience is necessary in order to encourage the interviewee to be reflective in their accounts, which is an important element of IPA.

A further reason for choosing interviews in my research, as opposed to alternative potentially non-verbal methods, was because in my professional experience, I had witnessed articulate young people with autism who were comparable to their peers in

this regard. I did not therefore want to collude with a potentially 'stereo-typical' view that young people with autism were typically less capable of expressing thoughts and feelings. Research which has explored the attitudes and perceptions of adults and young people towards those with autism, have indicated some misunderstandings and potentially negative thinking (Chambres, Auxiette, Vansingle and Gil, 2008; Swaim and Morgan, 2001). I believe that it is important to acknowledge but also challenge these assumptions.

I also contemplated using a more creative method alongside semi-structured interviews. However, although strategies such as photo elicitation have been shown to be successful with young people with autism, as a way of aiding discussion (Hill, 2014), there is a risk that it can also restrict discussion, potentially to the range of photographs or symbols offered to the child (Preece and Jordan, 2009).

My optimism in believing that young people with autism are capable of expressing their thoughts and feelings, was also balanced by a consideration of the associated difficulties experienced by young people with autism. This indicated that some modification of interview techniques might be necessary, as other researchers have suggested (Lewis, 2009). At times, I used closed questions at certain stages of the interview, for instance, to introduce new topic areas. It is possible that using some closed questions may have restricted the type of data collected but may equally have had a positive effect on rapport-building and potentially extended the interview. For Harrington et al. (2013) 'qualitative research with young people with ASD is a recently emerging field and little is known about the approaches that maximise their participation' (p154).

3.5.2. *The interview process*

In developing the interview schedule I was keen to explore the process of transition and although post-sixteen educational 'transition' can be identified as a distinct 'event' in itself (Breakey, 2006), it can also be described as part of a process that takes place over a longer time period (Nuehring and Sitlington, 2003). With this in mind, I was interested to explore experiences of education that had taken place prior to this transition.

The aim of the interview schedule was to locate transition in terms of the young peoples' past experiences as well as their hopes for the future. The first interview schedule therefore included: general experiences of secondary school; experiences of year 11 and

an exploration of short and longer-term plans after year 11 (Appendix 9). Interviews were recorded on a voice recorder.

The second interview (Appendix 10) took place early in November, after the participants had attended further education colleges for a six-week term and had recently returned from a short break. The intention was to explore their current experiences as well as their transition experiences retrospectively. I was interested in comparing how this related to their previously reported expectations and this also gave me an opportunity to check my understanding of their accounts. I had also noted individual differences in the topic areas that had developed in the first interviews and was keen to return to these, as appropriate, in the second interview.

On both occasions, in conducting the interview, I ensured that the participants were clear and comfortable with the research process and were aware that they could choose to terminate their involvement in the study at any point. Within both interviews, a 'stop' card was provided and its purpose explained to the participants at the start. This is consistent with the BPS guidelines (2018) which relay the importance of ethical practice in ensuring that vulnerable young people are protected. I reminded the young people that they could ask questions at any point of the study and that if they were not comfortable with any of the questions asked, there was no obligation to respond. I also ensured that I was sensitive to any signs of discomfort and that I utilised my active listening and rapport-building skills, in order to develop an effective and comfortable research relationship with my participants.

I had also pre-prepared a list of 'Useful websites' (Appendix 11) that I could pass onto my participants should particular topics arise which I was not able to adequately address in my role as a researcher. This included, for example, careers information websites as well as websites offering support with social and emotional concerns. Social and emotional difficulties in young people have been an increasing area of concern (Weare, 2015) and some studies have shown that young people with autism are at increased risk of developing these (Browning et al, 2009). It was my personal and professional responsibility therefore to ensure that this information was available to my participants, if required. The need to pass on this information did not arise.

Each interview lasted between thirty-five minutes and an hour. The pre-transition interviews all took place on the school premises in rooms away from the main thoroughfares. The post-transition interview, for two of the participants, took place in a room within the college. The third participant preferred to meet with me at his home, which I respectfully agreed to. The participants, throughout the interviews, waited for me to ask questions which may indicate that they had a sense of a power 'imbalance' in the research relationship (Greene and Hill, 2005), but at times, their responses were lengthy, which I believe illustrated that they felt reasonably comfortable with the interaction. I was careful to not 'probe' too deeply which could have resulted in their discomfort but their candid responses at times, may reveal that they felt at ease with the process. On one occasion, one of the participants was discussing his disrupted education timeline and I asked if he 'could tell me a bit more' about one aspect of it. Clues in his body language demonstrated however, that he was not sure if he wanted to share this and I immediately reassured him by replying 'of course, you don't have to'. As anticipated, he chose not to add more to his explanation. I think that this example demonstrates how I attempted to be sensitive to the reactions of the participants throughout the interviews.

3.5.3. Data analysis

I transcribed each of the interviews so that I was able to engage with them before analysing the data. In analysing the data from my participants, I followed the guidelines as set out by Smith et al (2009). This involved the stages as described:

Step 1 - Reading and re-reading the transcripts

I listened to the audio-recordings of the interviews before transcribing them and re-read the transcripts several times with the intention of becoming familiar with the data (Smith et al (2009).

Step 2 – Initial noting

This involved exploring the language used by the participants. Smith et al. (2009) advise that different types of notes are important, and these are explained under the following headings:

- **Descriptive comments**

This focuses on describing the content of the participant's account. This can include noting key words or phrases.

- **Linguistic comments**

This is more concerned with the type of language that the participant uses. For example, tone of voice, pauses and repetitions could be noted.

- **Conceptual comments**

These comments may have a more interrogative flavour and should be less focused on the descriptive or linguistic elements of the words used, but more on what they might mean.

I found it helpful initially to print out the transcripts and hand write comments in the margin (Fade, 2004). By following these processes, I was able to produce a detailed set of notes which then allowed me to begin a more interpretative process, in identifying emergent themes.

Step 3 - Identifying emergent themes.

In this step, I re-organised the data by adding an additional column on the transcript pages where emergent themes would be noted. The focus, in this step, was directed at the exploratory comments rather than the words themselves. It was important to reduce the data but maintain its complexity (Smith et al, 2009). An example of steps two and three can be seen in Appendix 12.

Step 4 – Identifying superordinate themes

At this stage, I ordered the emergent themes chronologically with the purpose of noticing patterns between them. The intention was to form clusters of related themes, by ordering and re-ordering them. I attempted to use different processes related to organising the themes but found the processes of “abstraction”, which involved putting similar emergent themes together, and “numeration”, noting the frequency that the theme emerged, as helpful during this stage (Smith et al., 2009, p. 96 and p. 98). This process was conducted for each interview which resulted in superordinate themes for each participant.

Step 5 - Searching for patterns

This final step demanded a degree of creativity in searching for patterns across individual cases. Master themes developed when patterns were recognised across individual cases. In following the guidelines of Smith (2004) for a master theme to emerge, it was required to be present in at least half of the sample. I was careful to acknowledge that the same theme or superordinate theme could “look very different in how it is evidenced across different participants” (Smith et al, 2009, p107).

3.6. Critique of methodology

IPA has significantly increased in popularity over the last decade (Smith, 2011). Alongside this however, possible limitations with the methodology have been identified. A concern highlighted by some researchers is around the amount of demands that IPA can make on the analyst at the different stages of the process (Larkin et al, 2006). In IPA, researchers are encouraged to draw upon a wide repertoire of analytical strategies which can be informed by prior experience and knowledge as well as psychological theory or previous research. It is essential, however, that they can be related back to a phenomenological account (Smith et al, 2009). For some critics, the number of ‘processes’ involved, may potentially have the effect of taking it further away from the participant’s phenomenological experience (Chamberlain, 2011). In response to this, I believe that it is the responsibility of the researcher to minimise this risk. I would suggest that, if the researcher is aware of this and can be consistent in moving within the hermeneutic circle, the possibility of this taking place will decrease.

Further criticism by some researchers (Willig, 2013; Todovora, 2011) suggests that the aim of IPA in focusing on an individual’s perception of experience, fails to explain the experience or be aware of the conditions that gave rise to it. These are conditions outside of the experience itself and are more related to its social context. I would accept that this is an important element of an experience but believe that experiences are naturally embedded within social contexts and a researcher should take account of this, when interpreting them.

3.7. The role of language in qualitative research

Speaking and interpreting language is undoubtedly a key component in most qualitative research and has formed the key means of collecting data within the current research. It is relevant to reflect briefly on the debate on the specific role of language in gaining an insight into the thoughts and feelings of our research participants. My position in epistemological terms, supports the view of Willig (2013) that perception is selective, and phenomena can be experienced in different ways and that language 'constructs' reality rather than simply describing it. This means that for all of us, our version of 'reality' may vary, to some degree, from day to day.

Using a language-based approach for research with young people who have potential difficulties with the communicative function of language may also add an additional complexity when interpreting data provided through interviews. The focus of IPA on observing the 'whole' rather than just the 'parts' however allows the researcher to explore the meanings of individual words within the context of the wider interaction (Smith et al, 2009). This may be a particular advantage when interpreting data provided by individuals in more vulnerable groups.

For Yardley (2000) it is essential to recognise the social context of the relationship and speech as an act of communication which will have specific meanings for listeners. As Yardley (2000) explains 'for most qualitative methods sensitivity to the linguistic and dialogic context of each utterance is crucial to interpreting its meaning and function' (p221). In Yardley's view it is impossible to remain neutral, so it is important to acknowledge the specific and general effects of the researcher. Examples of this include reflecting on the way that language is used within an interview situation and in interpreting the words. A researcher is also responsible for making decisions about how to label and organise data and this should be acknowledged as affecting the interpretation of meaning. Interpretation is an integral part of my chosen methodology and I believe that transparency and reflexivity in all aspects of my role, as a researcher, is essential for ethical practice. I have included some general reflections on reflexivity within the concluding chapter (Oliver, 2014).

3.8. Ethical practice

Ethical approval for the research was granted from the School for Policy Studies Research Ethics Committee at the University of Bristol in March 2017 (Appendix 13). I also referred to the British Psychological Society's Code of Ethics and Conduct (BPS, 2018) to ensure that I had adequately considered my professional responsibility within this process.

Throughout this chapter, I have considered ethical issues which apply to research with all young people and on occasions, more specifically to young people with autism. In choosing to focus my research on the experiences of young people with autism, however, for some people, this means that specific ethical issues arise (Milton, 2014).

An article by Milton (2014) raises ethical issues which he considers are specific to research with individuals on the autism spectrum. Milton (2014) claims that negative perceptions of autism have been promoted by some of the assumptions made by researchers. He proposes that notions such as autistic people lacking sociality is problematised and that being described as possessing "zero degrees of cognitive empathy" is at best discriminatory and at worst, "insulting and stigmatizing" (p794). In his view, this has resulted in some individuals with autism becoming distrustful of researchers and their aims.

I would accept that stereotypical assumptions can be evident in research with this population and one of the aims of the current study is to challenge these. In defence of researchers in this field, in general, I would offer that many researchers are well-intentioned and that there may be value in non-autistic scholars attempting to understand the perspective of those with autism, which can then be shared with them. As stated previously, I would accept that all qualitative research is an 'interpretation' of another's experience and that this should be as transparent as possible and clearly acknowledged within any study.

I would also propose that there may be a danger in Milton's argument (2014) if this was developed further and that only autism research which has been 'overseen' by autistic scholars has 'ethical or epistemological integrity' (p796). It is possible that this could be viewed as failing to appreciate the breadth of the autism spectrum and the differences between individuals on it (Grandin and Panek, 2013).

I believe that appropriate ethical considerations should be paramount in all research, regardless of the individual or group involved. These have been central in the current research and I have described in this chapter, how they have been regarded throughout.

In this chapter, I have provided a rationale for my choice of methodology in the study as well as explaining my position with regards to epistemology and ontology. I have also offered a general critique of the methodology. The strong focus on language within the research approach has led to debate on the interpretation of spoken language which I have briefly discussed. The chapter has also provided a description of the design of the study and the processes involved. In the following chapter, I will outline the findings in the study.

Chapter 4

Findings

4.1. Chapter overview

This chapter provides an account of the research findings. I will begin by analysing individual accounts and themes within them. I have chosen to use an ‘idiographic presentation’ which involves presenting the findings from each individual participant and identifying themes that have emerged. The interview themes are presented as pre-transition and post-transition stages with super-ordinate and sub-themes within each. These relate to the experiences of the participants towards the end of year 11 (pre-transition) and again, in year 12 (post-transition). Pseudonyms have been used to protect the identity of the participants.

Across both interviews there were shared meanings between the participants’ accounts in relation to certain themes. I have interpreted these shared meanings to further address my research questions and to more specifically understand the similarities and differences between the accounts of individual participants (Smith et al. 2009).

4.2. Jack’s story: Pre-transition

Jack attended an average-sized mainstream secondary provision. In his school life, he had a dedicated Teaching Assistant who supported him in most of his lessons. Outside of school, he enjoyed spending time on his Playstation and his mobile phone.

Throughout the interviews, Jack displayed real commitment and moments of insight in attempting to understand himself and his experiences.

Table 2: Pre-transition super-ordinate and sub-themes for Jack

Super-ordinate themes	Sub- themes
Self-perceptions	<ul style="list-style-type: none">• Emotional challenges• Excessive thinking
Finding answers	<ul style="list-style-type: none">• Perception of support• Negotiating identity
Leaving secondary	<ul style="list-style-type: none">• The past• Planning for the future

4.2.1. Self-perceptions

Emotional challenges

In meeting Jack for the first time, within a short period of time, it became apparent that strong feelings dominated his life. Within the interview, it was clear that anxiety was a principal emotion and that this had a significant impact on his thought processes. At times, he described feeling over-whelmed by different situations:

“Interviewer: What kind of things do you like to do when you’re not at school?

Jack: Try to keep myself calm and... especially at the moment, try not to worry about exams...dealing with my infection and concentrating on my exams rather than my infection”.

For Jack, the period immediately prior to transition, introduced a number of different challenges:

“And try and remind myself what days I need to come in...and what days I don’t... hear what’s happening after this week”.

Excessive thinking

The life that Jack portrayed was filled with emotional trials and the period directly before leaving secondary school presented him with further challenges. The end of term arrangements led to uncertainties for Jack who was predicting personal difficulties in managing these events:

“...and hoping that we don’t have to stay behind to collect our reports and hope when it’s the big assembly that I don’t feel tensed and worried....and when people are signing our tops...hoping that no-one’s going to put bad things on my top”.

This demonstrates the breadth of concerns that fill Jack’s thoughts. His tendency to engage in an excessive level of thinking was present throughout the interview.

In analysing Jack’s account, the repetition of the word ‘hope’ is perceptible and could be seen to reflect his lack of confidence in managing the uncertainties in his future. This was a recurrent theme throughout the interview.

4.2.2. Finding answers

Perception of support

Present throughout the interview was a sense that Jack believed that he required a high level of adult support to manage his life. He sought answers through the internet to find out “how to change or how I can stop myself” with regard to: “addiction to coke” as well as “being shy and scared around people”. It is interesting that he appears to provide a ‘list’ of concerns and I interpret this to mean that, at this time, he may feel that they are equally troublesome in his life.

Jack’s need for information and clarity does not appear to have been considered by others in his transition-planning. Jack explained that he had not been invited to any pre-transition planning meetings. This led to further anxiety for Jack:

“hoping that everything they’re saying is true ...and hope that they’re not storing anything in mind just because they don’t want me to know”.

Jack is cautiously optimistic about the support that is available within the college environment, stating that “...apparently there is experts”. His perception that he needs support to function effectively in life, is a recurring theme for Jack.

Negotiating identity

Throughout the interview, there is a sense that Jack is still ‘negotiating’ his identity and that this is a source of confusion for him. At times in the interview Jack recognised that there were some similarities between himself and his wider cohort, for example, in describing his out of school interests:

“Just as most teenagers do, go on their phone, or when I’ve got a moment go on the Playstation”.

For Jack, however, there were many differences that separated him due to his additional needs:

“I don’t understand things as easily as other people..... only having things on my mind for a few minutes, and then I start changing the conversation and forgetting something, so it’s hard for me to make decisions... “

There is a lack of information as to how Jack has acquired these beliefs but punctuated throughout the interview, these core perceptions of difference are observed by Jack.

4.2.3. *Leaving secondary*

The past

Jack discussed his past educational experiences in mainly negative terms. When asked about his feelings towards moving onto college, he identifies emotions which are familiar to him:

“Same as always, scared, nervous...hoping I get friends that live nearand hope it’s good there”.

I interpret his response to mean that these are the emotions that he experiences when facing a range of situations and are not unique to this one.

Jack was unable to think of anything positive to report about his years at secondary school and states:

“It’s been the same every year. I’ve always been the odd one out...”

This statement demonstrates a feeling of separation to peers that has defined Jack’s school experience. When attempting to explore his feelings further, Jack displays a glimpse of ‘optimism’:

“Soon, I’ll be able to smile and leave home and leave school, and I won’t have any exams to worry about”.

I interpret this to mean that, at the present time, these are all factors that constrain him.

Planning for the future

In exploring Jack’s planning for his further education college course, there was evidence that he had engaged in a level of ‘career thinking’ in his course decision. He had taken account of his skills and personal attributes and some clarity in his thinking is apparent:

“Interviewer: Ok, so how did you decide on carpentry and joinery?”

Jack: Because as I said I basically build things. Even though I get tired by it but I'm actually a strong lad. And I like being creative as you know from Minecraft".

This lucidity in his thinking, however, was balanced by some concerns that he had regarding the course:

"Interviewer: So, what do you think it might be like?

Jack: Scary, hard, sometimes injuries. Sometimes bullied".

This summary offers a real insight into Jack's thought processes and equally the number of concerns that dominate his thinking.

4.3. Jack's story: Post-transition

Table 3: Post-transition super-ordinate and sub- themes for Jack

Super-ordinate themes	Sub-themes
Moving on	<ul style="list-style-type: none">• Rituals• Sense of loss• Finding a voice
Relationships	<ul style="list-style-type: none">• The same but different• Adult support• Feeling vulnerable
Adjustment	<ul style="list-style-type: none">• New challenges• Negotiating identity

4.3.1. *Moving on*

Rituals

Within this second interview, I was interested to retrospectively explore the last days of secondary school and how Jack managed some of the end of year 'rituals' that he had been concerned about. In returning to these events, it seemed that Jack had used the strategy of 'self-talk' to reassure himself:

“Interviewer: How was the leaver’s assembly?”

Jack: Very hard, and just ...I didn’t know what to do with myself, but just sit there and deal with it, eventually it’ll be the end, and you’ve got Miss..... (Teaching Assistant) that is helping you with things”.

Jack described his last days, as “just stress” indicating that the anxiety which had been present throughout his secondary school had continued until the very end of his time there.

Sense of loss

Evident within Jack’s account, however, was a sense of loss regarding some of his past peer relationships, as observed in his reflections:

“Of course, now also being older and being all the way at college, course I can’t see the younger ones that I play with...”

Increasing maturity and practical difficulties meant that former relationships have ceased, which may represent a loss for Jack. The acknowledgement of “being older” also suggests that a new setting may require further exploration of his identity.

Jack also reported at this time that his negative experiences of college had the effect of “making me want to go back to school”. In the context of the rest of the interview, it is possible that Jack’s response could be interpreted as a wish to ‘escape’ a situation, rather than as a recognition that he had more positive experiences in the secondary school environment.

Finding a voice

I observed within this second interview that Jack’s tone of voice was more assertive than it had been in the first interview. A feature of this encounter was his tendency to ‘practice’ his responses to teachers, around current areas of disagreement and to a degree, a perceived sense of injustice.

Jack had experienced some frustrations with subjects which formed part of his curriculum. He appeared to believe that the teaching staff had underestimated his abilities around his independent living skills or “silly life skills” as he described them:

“Yeah and excuse me, not everyone has to put their hand up on a road to say thank you, as long as you just cross it then, you’re at least on the other side, and I know how to cross roads funnily enough”.

It is possible that the assertiveness that I observed however, was only obvious in our conversation. Jack explained that he found it a challenge to share his thoughts:

“Cos of my fear, I’m always too scared to tell literally anyone almost”.

4.3.2. Relationships

The same but different

Within this interview, in relating back to his early days of college, Jack shared his concerns over peer relationships. He spoke about “banterers” whom he had met on a previous visit to college and his difficulties in understanding their “sarcasm or joking”. Peer relationship difficulties that were evident in his first interview, continued within college and Jack implied that he needed to draw on his personal resources to manage these:

“I just knew “be brave” and hopefully you can even make new friends or carry on your addiction and be friends with them.” (In reference to friends from his previous school).

His choice of language is interesting here in describing his friendships as an “addiction” in the same way as he previously described his consumption of coke. This statement demonstrates his relationship dilemmas and appears to suggest that he feels a lack of control over his friendship choices.

In this new setting, Jack describes how he adopts a role of ‘safeguarding’ his friend:

“She *literally* needs me. See, if not, she would die already, of half the stuff she does”.

There is a sense that this responsibility is sometimes overwhelming to Jack, causing him “to not know what to do with myself”.

Adult support

Within college, Jack has developed new relationships with staff, and this has introduced some further dilemmas for him. He expresses a certain ambivalence about the teaching staff:

“I just know they’re teachers and some nice, but most...sort of nice, but at the same time some negative things about them”.

This statement suggests that Jack is attempting to find some balance in his views. However, his relationship with his tutor seemed to have deteriorated at this point and he reports that she is “being mean” to him.

In further attempting to understand these relationships however, he relates some of his concerns to possible misunderstandings created by his additional needs:

“I just don’t know if they’re being mean to me, as my brain says, or they’re just being strange teachers that think they know about autism, or ADHD, but don’t...”

It is my understanding that Jack has not found the ‘experts’ that he was anticipating in this new environment.

Feeling vulnerable

Throughout Jack’s account it is evident that he feels vulnerable within the new college environment and this is related to perceived risks. Some of his concerns are related to his interactions with peers:

“...cos I don’t know if they’re going to be nice, like some people, or they’re going to be extremely bad like some people....”

Jack alludes to certain people, from the past, who continue to pose a risk to him and his network of friends. As a reaction to this, Jack acknowledged that the presence of friends makes him feel ‘safe’ within the college environment:

“Cos in a way that’s why I find it hard to get myself away from, cos of knowing I don’t feel safe when I’m without her, or without any friend of any sort with me, and especially at the moment cos of changing group and everything”.

His words also indicate that timetable changes have an unsettling effect on him and have increased his feelings of vulnerability.

4.3.3. Adjustment

New Challenges

The college environment created new challenges for Jack and last-minute course changes and adjustments have caused confusion and annoyance for him:

“I’d just arranged all this with my respite carers, and getting ready for the transition course, just to find out I’ve changed course...not particularly happy about it”.

This suggests that Jack has had a minimal amount of notice about this change but also implies that there was a lack of consultation with him over this.

Further challenges for Jack are related to his journey, he was now required to walk to and from college. Jack described the high level of vigilance that accompanied this:

“looking down...looking to the sides and things, cos of being anxious of public, and what people are going to think of me.....”

It seems clear that this felt like an additional strain on Jack’s day which, as his story describes, was already filled with a significant amount of anxiety.

Negotiating identity

Throughout Jack’s account there is evidence that Jack is negotiating a new identity within this new environment. It is interesting to note that he compares himself positively to his immediate peers:

“Cos they all need support and help, even though I secretly do I still get on with it”

He also recognises that having the opportunity to develop his practical skills has been beneficial, as he describes his new work in the Children’s Centre garden:

“Interviewer: Did you like that?”

Jack: In a way, as it worked for my confidence”.

It is my interpretation that Jack feels a sense of satisfaction when describing these skills. He perceives however, that this competence does not mean that he can manage all of his needs alone.

“As I’ve always said to absolutely everyone...they seem to think cos I know everything, and Jack seems perfectly fine, I don’t really get any support and just...excuse me I do need it”.

Jack’s identity in this environment is still associated with a level of dependency. A lack of recognition by others is a cause of frustration for Jack.

4.4. Tom’s story: Pre-transition

Tom attended a resource-based provision for young people with social communication difficulties which was set within the grounds of a secondary school. He had joined this provision in year 10 following a period of home education, after leaving mainstream education. At the time of the interview, Tom was receiving all his education in the resource base.

Tom valued education and acknowledged that over the years he had missed out on a “full education”. His years in the resource base had largely been positive and he was able to take a number of GCSE’s at the end of year 11. Outside of school, Tom enjoyed listening to music and watching videos on You Tube.

In the interviews, I felt that Tom often demonstrated a reflective attitude and had a philosophical approach towards his experiences.

Table 4: Pre-transition super-ordinate and sub- themes for Tom

Super-ordinate themes	Sub- themes
Developing self-awareness	<ul style="list-style-type: none">• Life as a journey• Understanding self• A ‘guiding hand’
Future planning	<ul style="list-style-type: none">• Preparation• Managing change• Choices

4.4.1. *Developing self-awareness*

Life as a journey

Tom introduced the metaphor of a journey when describing this pre-transition period. The challenges that he faced contributed to his analysis of this time as “a hard journey”. Tom stated that the period in the resource base was the ‘most successful’ in his educational life, although it was still a time of anxiety for him. Tom explained that his anxieties in social situations meant that he did not “manage well” in mainstream:

“Erm, it’s been stressful but, in the end...I was able to accomplish entering exams, maths exams...”

This statement suggested to me that being entered for exams, signified for Tom, the culmination of his secondary school journey.

Over time, Tom suggested that he had developed the ability to reflect on his past:

“Because I feel that I have experienced a lot, and from my previous mistakes I have...I know what to do, and what not to do”.

Observations of his past appeared to lead to the conclusion that ‘personal failings’ were at the root of his difficulties and there was an assumption that he had a responsibility to correct these. This was a theme that was present throughout the interview.

Understanding self

In exploring Tom’s journey, he described the worst aspects of his pre-transition journey as “worrying my parents quite a lot”. He believed, however, that his emotional understanding had improved and that this was an advantage:

“I’m not really good at expressing my emotions really well, but I think I’m getting better at it, I think so”.

Tom’s developing sense of self-awareness can be observed in different parts of his account and there is a sense that this understanding is an ongoing process. This increasing self-awareness is evident in his reflections on his return to school, after a spell of home education:

“The challenge of...thinking and I remember that I like maths and, I like erm, ...talking really (laughs). It’s kind of a contradiction really, because I said a while ago that I didn’t like crowds. But ...I like, with people I know, talking really”.

This statement appears to suggest that Tom is attempting to understand his experiences, and this is a continuing process.

A ‘guiding hand’

In returning to school, Tom had the opportunity to form relationships with his peers following a period of home education. I was interested to explore how his relationships had developed:

“Interviewer: So, have you made friends in the...centre?

Tom: Erm, not friends, but I would say people that I know, that I respect, and that I can talk to”.

This was an intriguing description and in the context of Tom’s previous comments, did not appear to equate to a lack of interest in others. Tom still valued the support of others, as he describes:

“I always feel that I would need a guiding hand, someone to talk to sometimes”.

4.4.2. Future planning

Preparation

In discussing future career ideas, Tom explained that “engineering is my long-term passion” and this was related to his interest in mathematics and science. Tom’s choice of college course bears little relation to this however, being more focused on the acquisition of independent living skills:

“...because I would like to learn to be independent really. Learn to do the cooking...or learn to do the laundry and stuff like that. I want to...like be independent”.

In preparing for his move to college, Tom was not involved in any formal transition-planning meetings and stated that “there was no need to speak to me”, a belief that was

based on a lack of formal entry requirements for his course. This may have indicated that some decisions regarding his transition were made without him.

Managing change

In contemplating the significant changes ahead, a theme that developed within this interview was Tom's management of change, in general. He described how he "hates change", acknowledging that he will "worry about it". He described using distraction to help him:

"Erm, I play...I listen to music. I play games and...I just...and I just focus on something different".

Tom had experienced many changes in the past and as he explained, this resulted in him adopting a passive acceptance to it, which was reflected in his behaviour:

"Erm, I always feel that something is going to happen that is going to...make me need to change. So, I always keep it vague I think".

There appeared however, to be a meaningful degree of trepidation in his attitude towards change:

"You don't know what's going to happen, but you know it's there. It's going to come".

Choices

In further discussing Tom's future plans, it became apparent that his choice of course had been based on advice from others as well as trusting his own emotional reactions:

"I just felt, well they told me, and I felt that I should do it by what I think feels right".

In assessing the wider opportunities available in college, Tom dismissed the idea of social or activity clubs:

"Interviewer: Do they have clubs...do you think you would like to go?

Tom: Yes. I would say I would like to ...but my personality, I would ...say realistically I would not be able to do it".

I interpreted this as meaning that Tom had acknowledged that his ‘personality’ could have a restricting effect on him. In my opinion, a sense of acceptance was present within this statement.

4.5. Tom’s story: Post-transition

Table 5: Post-transition super-ordinate and sub-themes for Tom

Super-ordinate themes	Sub-themes
Moving on	<ul style="list-style-type: none">• Leaving school• Attachments• Social anxieties
New experiences	<ul style="list-style-type: none">• Challenges and opportunities• Steps to independence• The future

4.5.1. Moving on

Leaving school

In meeting Tom for the second time, he described his feelings of apprehension as he left school. Already at this early stage, he was predicting his possible future difficulties:

“Interviewer: Do you remember feeling anything in particular when you left?”

Tom: Erm, kind of scared, because I got kind of...I don’t know how I was going to handle the mornings, and...getting there. So, I was kind of...uncertain”.

It was evident that Tom’s concerns about bus travel, as described in the first interview persisted, as he left secondary school.

Attachments

In discussing leaving the support staff in the resource base, Tom confirmed that he did not experience any personal attachments with support staff:

“...I don’t really form any like personal connection with my teachers really”.

He also does not express any regret at leaving peers, suggesting that “I might see them around town, so I’m not really sad...”, Tom seemed to suggest that not having emotional attachments to others is liberating for him:

“So I can move on, from where we were”.

Social anxieties

One of Tom’s overriding concerns expressed in the first interview was his anxiety around “crowded places”. Within the busy college environment, he had developed a strategy to support him with this:

“It’s...ok for example, the canteen is kind of crowded, but I can sit down and look at my phone.”

The purpose of this was, “pretending that I’m busy”. He also used it as a tactic to distract himself from worrying about unkind comments from others. He explained, “I can be annoyed that some people criticise me”. It is unclear whether there had been recent incidents or if he is recalling past experiences.

Further anxieties for Tom, within this early period included induction activities. This had involved one particular activity where students had to share personal information with each other. Tom described this as “scary” because “this was the first impression that you have to make”. This may indicate that Tom was concerned that he may be negatively judged, which he had experienced in the past.

4.5.2. New Experiences

Challenges and Opportunities

There were some positive features of an extended induction period, which Tom described as a more “gentle introduction”. This did not completely allay his fears of starting his course however, and Tom describes being ‘cautious’ about this.

For Tom there were also different opportunities within the college environment, and a ‘flexible’ and empathic approach by staff was appreciated:

“Sometimes, I forget equipment and stuff, but I know that I can ask them, and they would know and understand”.

Tom's course included work experience in a café, and it became evident during this interview, that this had introduced a number of challenges for Tom:

"I can't...um...I find it trouble remembering what people say, so I would have to write it down again".

The café experience had caused Tom some anxieties about returning to college at the beginning of the new term and he had expressed some reservations about this:

"I was feeling kind of stressed in (café) and I had a day off because I was feeling sick, and I didn't really want to go to college and erm..."

In response to this, Tom shared with me, that he had spoken to a CAMHS (Child and Adolescent Mental Health Services) therapist about this and this had been part of his routine for at least three years. This suggests that, at this time, Tom's work experience had caused him a significant level of distress.

Steps to independence

Tom's course introduced him to a number of 'independent living skills', and he seemed pleased to report that his cooking skills were evolving and "that it was probably a good thing" that his mum would encourage him to practise these skills at home.

Without knowing the full details of Tom's past life, there was evidence in his story that underlying anxieties had prevented him from engaging in a range of activities in the past. He reported that he was pleased to engage in positive new behaviours which he told me that he would not have had the "courage" to participate in "two or three years ago":

"Erm, now I can, for example yesterday I had the courage to go...after school, I got off the bus and went to Asda, and bought some...I gave like £2 to charity for poppies".

It was my interpretation that this new behaviour was important to Tom, representing small steps towards greater self-confidence and independence.

The future

In common with the first interview there continued to be a sense of self-deprecation in some of Tom's reflections. For example, he described his "bad memory" and his poor

organisational skills. Tom persisted in describing his difficulties in terms of his “bad habits”:

“Interviewer: Do you feel any different now that you are at college?

Tom: I wouldn’t say different, but I’m improving my bad habits”.

Tom responds candidly to my question but there is still a sense within his story that he was expecting this ‘improvement’ to be a lengthy process.

4.6. Adam’s story: Pre-transition

Adam attended an independent specialist provision which he had commenced two years previously. This followed the breakdown of a mainstream secondary placement. In this provision, Adam was required to repeat a year due to periods of missed education. In this provision, he had access to small group learning and full-time Teaching Assistant support. Outside of school, Adam enjoyed playing video games, using his tablet and meeting up with friends for shopping trips and eating out.

In the time that I spent with Adam, he revealed a high level of curiosity about aspects of life and displayed a unique sense of humour.

Table 6: Pre-transition super-ordinate and sub-themes for Adam

Super-ordinate themes	Sub-themes
Relationships	<ul style="list-style-type: none">• Importance of relationships• Challenging relationships
Planning	<ul style="list-style-type: none">• Short-term planning• Curiosity

4.6.1. Relationships

Importance of relationships

Weaved throughout Adam’s story, one of the key defining themes was his interest in other people. He was immediately curious about my life and the reciprocal nature of parts of the interview, suggested to me, that he enjoyed the interaction.

Adam's account was punctuated throughout with examples of his connections with others. In reflecting on his experiences at his current school, the 'good parts' involved his relationships with friends:

"Interviewer: What were the good parts of (current school)?

Adam: Friends I had. Getting on with people".

In reflecting on the 'worst thing' about his school experience, Adam reported that not all his relationships were positive and described how his school experience was affected by "the enemies that I had".

Further in the interview, in contemplating the opportunities provided by starting college, relationships again were key:

"Adam: ...I'll probably get more opportunities and things.

Interviewer: What sort of opportunities do you mean?

Adam: Well, probably more to do...Getting to meet new people".

"Knowing people" at his new college seemed to reassure Adam. Throughout the interview there is a sense that Adam's experiences are defined by the relationships that he has made.

Challenging relationships

In discussing this pre-transition period Adam described the strong feelings that were provoked by certain people. This involved relationships with teachers as well as peers:

"Well, there were people I didn't get on with...there were teachers that I hated. ... So, I used to hold a big grudge, if I hated them".

He recognised that his relationships with teachers had a direct effect on his enjoyment of subjects:

"If I hate the teacher then I'm not going to like their lesson".

And later in the conversation:

"Interviewer: So that kind of spoiled things for you, do you think?

Adam: Yeah. Because I hated them a lot and refused to get along with them”.

This apparently uncompromising attitude had consequences for Adam, in that he was required to terminate some GCSE subjects. Adam explained why his relationship with one teacher had deteriorated:

“Well...constantly... shouting all the time. Or telling me to do something that I didn’t want to do... I didn’t want to take my watch off”.

This indicates that the combination of these factors was difficult for Adam to tolerate and indicated a perceived lack of flexibility by staff.

4.6.2. Planning

Short-term planning

Adam had been offered a place on a Media course at college and this was based on his interests outside of education and was related to an occupational area that he believed that he would enjoy:

“Interviewer: So how did you decide on Media?

Adam: It’s just what I like most, like films and things...”

Adam believed that it could lead to a role in the creative industry.:

“something like a film critic...someone who writes reviews for films...or maybe says them on the telly, or something”.

This ambiguity revealed that he had not explored this career area in any particular depth.

Curiosity

Adam displayed an uninhibited sense of curiosity at different stages of the interview. Matching salaries with careers captured his interest and Adam became more animated at this time and revealed an eagerness for detail:

“Adam: How much could you get for it (media work)? ...Well I think that a salary for most people is about thirty-two grand”.

Adam's curiosity extends to include more general interests, exclaiming "well I actually want to see what the twenty second century will be like" and suggesting that he would "like to see if world war three happened". At times, this energy is captivating. The enthusiasm present within this part of the interview however had been much less evident when discussing his immediate transition plans.

4.7. Adam's story: Post-transition

Table 7: Post-transition super-ordinate and sub-themes for Adam

Super-ordinate themes	Sub-themes
Continuation	<ul style="list-style-type: none"> • Focus on relationships
Into the future	<ul style="list-style-type: none"> • Independence • Longer-term planning

On meeting Adam for the second time, the plans that he had discussed in the first interview had dramatically altered. Both the college that he was attending, and the course had changed. This was related to Adam failing to meet the entry requirements for his chosen course. He was now studying for a foundation level course covering a variety of topic areas.

4.7.1. Continuation

Focus on relationships

Adam implied that he had accepted the change to his original plans:

"Interviewer: How did you feel about going to a different college?"

Adam: Well...I knew people who were there, and I mean it seemed like big enough for me".

As in the first interview, familiar faces at college were important for Adam, and I interpreted this to mean that relationships were key to acquiring a sense of 'belonging' in his new provision.

Adam also returns to the theme of relationships when I attempt to explore his feelings about his new course:

“Interviewer: What do you like about your course?”

Adam: Well...well...I just get on with like teachers, and other students”.

This theme continues throughout the interview and in considering what he misses from his pre-transition days, he states that he doesn’t “exactly see friends from...any more”, again stressing the importance of past as well as present relationships. His post-transition experiences are defined by this theme, in the same way that his pre-transition experience was.

4.7.2. *Into the future*

Independence

Adam explained that he had become accustomed to college life and reported that one benefit was that he had become “more independent” there. Independence, he described in terms of a greater level of freedom and further opportunities. Walking into town and having a “bite to eat” with friends was part of his new freedoms:

“Well, we’re allowed to leave the college sites at certain times. And, like, there is a lot more to do”.

Adam was also feeling positive about his learning and explained that he found all the modules that formed part of his foundation programme to be “fun to a certain extent”.

Longer-term planning

Adam’s course included an element of work experience and I was interested to find out more about this:

“Interviewer: Have you been asked what kind of placement you’d like to do?”

Adam: Well, probably film critic or something, but I think in the meantime I’ll be doing a bit of work around here...probably fixing things”.

Adam’s anticipated work experience appeared to represent a significant mismatch between his interests and the placement offered. In exploring longer-term plans, the talk

of salaries energised Adam, in the same way that it had, in the first interview. Financial considerations had also influenced some of his longer-term thinking:

“I mean I want to get a good job; I can get a lot of money for doing”.

He had also taken this into account when thinking about longer-term decisions regarding his future education:

“But...it (university) could be a bit much. I mean you could be there for some time, and it would be awfully expensive”.

Each of these parts of the conversation led to further interesting discussions. This reflected that Adam had engaged in different aspects of deliberating his longer-term future. It was my impression however, that he had not made any specific associations between them.

4.8. Matt’s story: Pre-transition

Matt attended a large mainstream secondary provision, which he had commenced in year 10. He had originally lived in another part of Europe. He moved to England with his father during his secondary years and lived in a London suburb where he experienced a large number of unsuccessful educational placements. Following this, he returned to his home country where he attended a specialist provision before returning to London briefly before settling into the local authority in which the study took place.

In his spare time, Matt took part in the Army cadets and was completing his bronze Duke of Edinburgh award with this group. He also enjoyed playing video games.

Unfortunately, I was unable to meet Matt after he had left year 11 because, as I understand, on completion of his GCSEs, he unexpectedly moved back to his home country. I have included his pre-transition interview in the study because he was keen to be involved in the study and it had seemed important to him that his experiences were understood by others. Inclusion in the study will hopefully go some way towards this.

Table 8: Pre-transition super-ordinate and sub-themes for Matt

Super-ordinate themes	Sub-themes
Understanding	<ul style="list-style-type: none">• Understanding self• Values
The future	<ul style="list-style-type: none">• Autonomy• Support• Sense of purpose• 'Wait and see'

4.8.1. Understanding

Understanding self

On meeting Matt, he was eager to talk and would often supplement his answers with reflective comments. My interpretation of this was that he hoped to clearly explain his experiences to me, but also that he was continuing to make sense of them himself. His narrative indicated that, over time, a growing self-awareness had allowed him to do this.

He described his earlier educational experiences of attending nine or ten different school in one year, after being “kicked out”. Matt reported that with ‘maturity’, he developed an increased level of self-awareness:

“Yeah, I think that I was younger I didn’t know what I was saying, and I just said before I thought.... “.

Matt believed that his confidence had improved during this pre-transition period and that this was related to an increased level of interaction with others:

“...just coming in every day, meeting new people and talking to them, that builds up your confidence in making friends and communicating”.

Matt’s conclusion was that he believed that he would be rewarded for acquiring more ‘positive’ behaviours, but it is unclear at this time what Matt considered the ‘rewards’ would be:

“but now because I’ve grown up, I’ve got more mature and started learning that...if you do something good then you’ll get something good back”.

Values

Matt’s increasing understanding of his past was supported by some clear personal values. In describing his relationships with others at army cadets, his views on inclusion were demonstrated:

“In the army cadets you don’t get judged, like disabilities or something...you all get treated the same and I think that’s pretty good”.

This contrasted with his initial school experiences:

“Interviewer: so, do you feel that sometimes you are judged?”

Matt: In school yeah, but when I’m there (army cadets) I feel that it’s kind of like a safe environment”.

This statement indicates that Matt feels more protected in a climate of equality, where he does not feel judged for any perceived differences.

4.8.2. *The Future*

Autonomy

In discussing his future career plans, Matt explains clearly how his plans have progressed:

“...I looked at what I liked, and what I enjoyed doing in school, what I want to do in the future and I just decided from there”.

There is a sense in this account that Matt was single-minded in his approach and he admitted that he is “pretty good at deciding my own decisions”. In response to my query about access to more formal transition arrangements, this independence is again observed:

“Well I wasn’t offered it, but I don’t need it anyway...”

Support

For Matt, difficult past experiences meant that it took him a while to trust the intentions of others. When he was 'ready' to accept support, Matt was grateful for it:

"Well the best thing is how polite staff are and how they're willing to help... and I'm really thankful for that".

He valued support from school staff when it was delivered discreetly:

"It's nicer knowing that there's somebody there, so if you're stuck on something they'll come and help you...because I don't want them sitting next to me all the time, because I think that's pretty annoying..."

He did not feel the same sense of support with his pre-transition planning from the Careers Advisor, who did not have a good understanding of his interests or ambitions. She had suggested careers in animal care and engineering which were not of interest to Matt so he "stopped going".

Sense of purpose

In describing some of his previous experiences, Matt indicated that some of his decisions were related to his future career development. He, for example, recognised the value of the Duke of Edinburgh award, because of the employability skills that it evidenced:

"And you get a good thing for your CV...The Duke of Edinburgh is also not just an expedition, but community work as well, so they can see that you're good at working with the team, and it's more likely that you get the job".

Matt had strong career ideas and had been committed to a career in Information Technology for many years stating that he would like to start his own business in computer hardware and had chosen the most suitable college course for this. He had "looked at all the courses and decided that it (IT course) was the best one".

Earlier in the interview, Matt shared his belief that education was "really important" to him, a view which was supported by his father. Matt's approach to planning for the future may indicate that he was equally committed to this.

“Wait and see”

In other respects, however, Matt adopted a more nonchalant attitude towards some of the details in his planning:

“Interviewer: Do you think that college is going to be different to school?”

Matt: I don’t know, I haven’t experienced it yet. Just wait and see...”

With respect to his longer-term future, he took the same approach:

“Yeah, I just wait until it comes. Because I can’t see into the future, so just wait...see what happens”.

The amount of change that had previously occurred in Matt’s life may add further relevant context to these comments.

4.9. Findings at group level: Pre-transition master themes

The final stage of analysis in IPA, according to Smith et al. (2009), is to search for patterns across cases and generate master themes. In my study, a number of recurrent themes were recognised when the individual accounts were analysed together.

I have again chosen to present the findings in terms of pre-transition and post-transition experiences in order to recognise the similarities and differences between them.

Table 9: Master themes from the pre-transition interviews

Super-ordinate themes	Sub-themes
Relationships	<ul style="list-style-type: none">• Peers• The support of others
Understanding self	<ul style="list-style-type: none">• The passage of time• Feeling different
The future	<ul style="list-style-type: none">• Change• Making choices• New opportunities• Anxieties

4.9.1. Relationships

Peers

In exploring the pre-transition experiences of the participants, peer relationships are a key theme across their accounts. For these young men, additional difficulties relating to social communication and interaction, were experienced. Differences were described in their relationships with peers, and in my interpretation, to their expressed desire to 'fit in' with peers. For Jack, he had felt apart from his peers for many years and there was a sense that they had not always been kind to him:

“As I say it’s been the same every year. I’ve always been the odd one out...worrying all the time about...especially bullies, because they were worse in primary”.

Jack was most vocal in expressing his specific difficulties. For example, he identified “banterers” on a pre-visit to college. ‘Bantering’ he suggested is “similar to sarcasm and joking” neither of which he reports to understand. Jack had been promised a ‘transition course’ that he believed, would support him to acquire a better understanding of his peers.

Specific difficulties related to social misunderstandings are less explicit within the accounts of the other participants. It is very evident in Adam’s story however, that peer relationships had introduced some challenges in his life. Relationships for him, were a source of comfort and he described his friends as the “biggest help” in his life, but other relationships were also at the root of some past difficulties.

In Matt’s story, his reflections on his relationships with peers in his current school suggested that positive relationships had not always been a feature of his past experiences:

“When I first started in year 10, my past experiences meant that I was very nervous about meeting new people...and I saw that people wanted to be my friend”.

For Matt, at this time, however, he still considered that the army cadets provided a less 'judgemental' environment than school, suggesting that he was able to 'fit in' better in this setting.

In Tom's account, although he recognised that he enjoys 'talking' to people, his social anxieties could be debilitating:

"...because unless I know the person and the group of people, then I won't really talk to them".

This social anxiety was also present in Jack's account, reporting that he felt "scared" around peers, as well as adults.

For Tom, however, his relationship difficulties do not appear to torment him in the same way as Jack. He is also not explicit in expressing a desire for closer relationships, which had seemed important to Adam. It is possible however, that Tom's anxieties concerning social interaction are a factor in this.

The support of others

The theme of the benefits of support offered by other people was evident across the four accounts. The support discussed by the participants related to support available within school by support staff and specific advisers, as well as that offered by others in their lives. There were, however, differences in their preferences to how this support was received.

Although Jack had significant teaching assistant support in his lessons, this was barely acknowledged in the first interview but there was a sense that he relied on a wider group of adults in his life, such as a social worker, his parents and respite carers. He resorted to information on the internet to find answers, to a range of difficulties, if his 'supporting' adults were not available:

"How else am I going to sort my issues out when I haven't got my social worker with me and I've not always got somebody to tell my issues to".

For Adam, the level of support that he had access to in school, was “the right amount”. It may be significant however, that Adam attended a specialist provision for young people with social communication needs, which proffered him a high level of individual support.

The support of others was visible in all accounts, but the preferred ‘style’ of support differed between participants. Matt identified teaching assistants in school as a means of support, but suggested that its value was greatest when it supported his specific goals:

“I think that’s a nice way to introduce someone to the school, give them the support they need to achieve what they want”.

This seemed in contrast to Jack’s view. He suggested that he relied on adult support to assist him with managing many different aspects of his life. In Tom’s story, his description of a “guiding hand” appeared to imply that he appreciated support that was available at key times. This was more akin to Matt’s view.

4.9.2. *Understanding self*

The passage of time

There was a sense within the accounts of the participants that the passing of time had led to new personal understandings and this was especially evident in the accounts of Matt and Tom. Matt explained that increasing maturity had meant that he had reduced certain behaviours, and as a younger child, “I didn’t know what I was saying”. For Tom, over time he also seemed to have developed more self-awareness, stating that he could “learn from past mistakes”. He also recognised that his ‘personality’ meant that he needed to accept some personal limits.

For Jack, the passage of time, had not altered his thinking in the same way as the other participants. Although Jack seemed desperate to increase his understanding of himself and others, in reality, new situations created further opportunity for confusion and misunderstandings.

Feeling different

In the stories of the participants, the theme of ‘feeling different’ was visible in all of their accounts but they had individual approaches to managing this. For Jack, his additional

needs meant that he was “not normal”. His perception was that he needed adult support to “get back to what a normal person would be”.

For Adam, he defined himself as someone who finds life “more difficult” than his wider peer group but did not express strong opinions about how this might be resolved.

Tom’s differences were described by him, as “bad habits” and there was a sense that he was independently striving to make some progress on these. In Toms’ description, his reference to a “normal” person may indicate that, although he appears to suggest otherwise, he is inadvertently comparing himself to others and their perception of normality:

“There’s no such thing as a ‘normal’ person, but there’s...I think in a...I always think of the negatives before I think of the positives”.

In Matt’s story, although he explains his ‘differences’ early in the interview, his account overall seems to indicate that he is more focused on recognising the similarities between himself and his peers rather than the differences between them.

4.9.3. *The future*

Change

For all participants, concerns over managing change were highlighted in each of their accounts. Change was the cause of some anxiety for each of them. In his characteristically under-stated way, Adam, described change as “a bit worrying”. Matt explained that he “can’t get used to it that fast” but at a slower pace, he was able to adapt more effectively:

“I’m fine with change, but it’s like (long pause) slow change, not like immediate, like, you have to do this”.

For Jack, change further fuelled his high levels of anxiety and his quest for ‘finding answers’ meant that any change generated a further set of questions. For Tom, he confessed to “hate change” and to “worry quite a bit” when changes were due to take place.

For each of the participants they had developed individual strategies to manage change. Tom described distracting himself: “Erm, I play...I listen to music”. He also explained that

he was encouraged by his mother to look beyond immediate concerns and concentrate on the “the bigger picture”. For Tom, this “sometimes” helped to reduce his anxieties.

For Adam, similar to Jack, he “will try to find out more about it” and for Matt, he explained that he chooses to, “practise it” so that he “got used to it”.

In considering the significance and the many changes that accompany this transition period, all of the participants expressed little interest or knowledge of formal transition processes, including transition meetings. Jack reported that he did not attend any meetings because “it’s not for me”. Matt stated that “he didn’t need it” (transition support), although it wasn’t offered to him. Tom believed that it wasn’t relevant to him because he “didn’t need particular grades” for his course. The purpose and function of more formal transition processes seemed unclear or even unnecessary, to the participants.

Making Choices

There was some evidence in each of the participants’ accounts, that they had employed a level of ‘career-thinking’ when making their post-secondary choice. For Jack, Adam and Matt, their course choice was directly related to their interests outside of school and in the case of Jack and Matt, to their perceived skills or abilities in their chosen field.

Jack stated that his choice of a course in Carpentry and Joinery was related to his interest in being creative, as well as the skills that he had acquired through “building things” such as a: shed, rabbit run and shelf.

For Matt, his interest in computers increased over time until he “was really interested in it” which resulted in this being a focus for his course choice. For Adam an interest in ‘film’ was the main factor in applying for a media course but his exploration of related careers had been at a more superficial level.

The exact reasons for Tom choosing a course which focused almost entirely on independent living skills is less clear but his wish to be ‘independent’ was a factor in this, describing how this meant he could “...sort out my money, and go the bank....and re-do my passport”.

New opportunities

For each of the participants they were able to identify benefits of moving onto college and this was a theme in each of their accounts. Jack was optimistic about the new opportunities provided by attending college:

Jack: "...making new friends and hopefully better times of the day, and not having to come in every day, and hopefully having better support".

For Tom, he mentioned some similar benefits as well as envisaging that a different 'style' of relationship with adults may be possible in this environment:

Tom: "...by allowing us to speak to the teachers, by saying their first names, I guess it gives us equal standing".

Adam could also appreciate that a "new start will be exciting" and comparing school and college, experiencing greater choice was an additional benefit:

Adam: "...probably more doing something that I like than what I *have* to do".

Matt had a more philosophical approach when reflecting on his move to college:

Matt: "I don't know, I haven't experienced it yet. Just wait and see".

For all the participants there were practical reasons for their choice of college and for three of them, this was based on the location of the college, being the one nearest to their home. For Adam, the aesthetics of the college were an important factor in informing his choice of placement. He explained that the college "was just a nice place" and a place where he felt comfortable.

Anxieties

Anxious feelings were mentioned regarding aspects of the transition process in each of the participants' accounts. For two of the participants the move to college was a source of considerable anxiety. Jack confessed that his anxieties were similar to those he felt when confronting a number of different situations:

Jack: "same as always, scared, nervous".

For Tom, his concerns at this stage were more focused on specific anxieties, including his journey to college and the need to use public transport:

Tom: “I was kind of erm...stressed I would say, over (pause) the bus mostly, but anything else was kind of fine, really”.

For Adam and Matt, their concerns were more related to their dislike of change. Adam stated that there was some risk attached to change and was concerned that he “might not like the change”.

4.10. Findings at group level: Post-transition master themes

Table 10: Master themes from the post-transition interviews

Super-ordinate themes	Sub-themes
Continuation	<ul style="list-style-type: none">• Relationships• Anxieties
The past	<ul style="list-style-type: none">• Repeating patterns• Resilience• Sense of the future

4.10.1. Continuation

In the second interviews it was my impression that themes that had been noted within the first interviews continued to influence the participants in their new environments.

Relationships

Relationships had been a key theme for all participants, with experiences of both positive and negative relationships being evident in their pre-transition accounts. This continued to be a theme within college.

For Adam, his emphasis on positive relationships continued to be important for him, appearing to support a sense of belonging and allowing him more social opportunities:

“Interviewer: So, have you got used to going to...college.

Adam: I’ve made friends

Interviewer: What do you do with your friends?

Adam: Go into town, get a bite to eat”.

In his interview, Jack had spoken in detail about a small group of female friends who had moved onto college with him. The new role that Jack had adopted, in ‘protecting’ his friends, was not a role that he was completely comfortable with. Within this college environment, Jack’s relationships continued to be a source of increased anxiety for Jack, which threatened to overwhelm him in a similar way to other concerns expressed in his first interview.

Jack: “And just dealing with X all the time, and I don’t know who to help, and how to help them, and sort of dealing with Y at the same time”.

Jack continued to remain separate to a wider group of peers. The ‘bullying’ that he spoke explicitly about in the first interview is not as directly referred to within this second interview but is still a significant underlying issue for Jack. Within Tom’s account, negative interactions were also briefly alluded to.

In Tom’s first interview, he described forming ‘respectful’ relationships with peers. This pattern seems to have continued:

“Interviewer: Have you made friends with any other students?

Tom: Erm, I think not yet, but we do have common interests...we can talk”.

Anxieties

Anxiety continued to be a feature of the experience of some of the participants after moving onto college. For Jack, continuing uncertainties around course changes and confusing information meant that he ‘feels a bit worse’ about college than when he first joined.

Tom explained that the work experience element of his course, had caused him considerable anxiety:

“Erm...too stressful. It was...I can...only tolerate so much stress in a day...”.

At this stage, Tom is able to share his concerns by talking with his CAMHS therapist, but he is concerned that this may change when he reaches eighteen and transfers to adult services, explaining “I will see after next year as to how things go”.

For both Tom and Jack, this suggested that anxiety was likely to be an ongoing issue that, at times, they did not feel able to manage alone.

4.10.2. *The past*

Repeating patterns

In the past, for three of the participants, they had endured significant periods of disrupted education. Similar periods of uncertainty continued for the participants and became a theme in post-transition interviews.

At the time of the interview, adjustments were still being made to Jack’s course with resulting confusion and anxiety for Jack:

“Interviewer: What do you do on your course?”

Jack: Now I’ve moved to...group, I don’t really know. I’ve only been there for three days

Interviewer: Were you expecting that change?

Jack: No and that’s another reason why this week has gone terribly badly”.

Adam was required to re-take his GCSE English exam and this worried him, in case it was “another burden”. Tom was also required to adapt to a new timetable and staffing shortages meant further changes to his timetable, again resulting in a level of confusion:

Tom: “Erm...Fridays, we...well...this term because it’s short-staffed, sometimes on Fridays we...go...and do a subject called....”.

For Jack and Tom, this was an unsettling period. It was unclear, at this stage, how it would be resolved.

Resilience

In the second interview, new themes were also developed. Resilience was a theme that could be more explicitly observed in these interviews. Tom indicated a certain resilience in his approach to college. He suggested that he was becoming “used to the buses” and “ordering food in the canteen”. He also predicted that his past experiences indicated that he would become accustomed to his work experience in the café:

Tom: “Erm, I think that, with like everything that I do, I think that I will get used to it”.

This was also evident in Jack’s account and although, he didn’t seem to recognise it himself, Jack revealed a certain resilience in managing some situations:

“Interviewer: Were you ready to move on (from school)?

Jack: Not necessarily ready, but yeah, I knew I’d end up liking it”.

For Adam too, he was able to adapt to the changes that were enforced:

“Interviewer: How did you feel when you were told that you weren’t going to ...college?

Adam: A bit disappointed, but I decided that.....college would probably have its good points”.

The personal strategies that the participants had developed were evidence of their resilience. For example, Jack gave many examples of using self-talk to help him manage situations that were difficult for him. He also attempted to reduce his anxieties by clarifying his understanding of certain changes within the college setting, through contacting college staff via email. This unfortunately had limited success in not always receiving responses from members of staff. “Finding out more” was also a strategy used by Adam.

Sense of the future

With all of the participants there was a sense that the experiences of the past had an influence on their expectations for the future. In Jack’s case, he anticipated that new situations would be the ‘same as always. His past lack of success in managing difficulties

in the past, seemed to affect his confidence in 'solving difficulties' in the present. The transition process and moving onto college had introduced a range of further issues for Jack to attempt to resolve:

“Interviewer: Ok, do you think eventually you do solve the difficulties you have?

Jack: Pretty much never”.

As observed in the interview with Tom, his past experiences impacted on his future aspirations. He seemed to have reacted to past unpredictability by keeping “plans vague” and presented as a passive recipient to change. His career “calling” to be an Engineer seemed more distant once he had moved onto college. In the second interview, there was also little evidence of Adam adopting a more active role in pursuing his career ambitions.

4.11. Chapter summary

Throughout the stories of the four participants, it was clear that specific barriers existed for these young people when considering their post-sixteen transition and although there were supports available, these did not always seem to be sufficient. The significance of the barriers depended to a degree on the individual needs and personalities of the young person. It is likely that the past experiences of the participants, also factored in their response to transition.

Despite this, there were some similarities that connected them, in their experiences prior to transition and following transition, and these have been demonstrated by the joint themes. In the pre-transition phase these include: Relationships, understanding self and the future. In the post-transition phase, these are: Continuation and the past. The implications drawn from these findings will be discussed in the next chapter.

Chapter 5

Discussion

5.1. Chapter overview

In this study, I aimed to explore the experiences of young people with a diagnosis of an autism spectrum disorder (ASD) as they left secondary education and moved onto further education. The previous chapter outlined the findings from the analysis of each individual young person and the master themes that developed between them, both in the pre-transition and post-transition phases.

The aims of the current chapter are:

- To explore how the findings address the research questions of the current research.
- To outline how these findings contribute to the existing literature.
- To examine how the findings can be understood in terms of current psychological theories.
- To outline the strengths and general limitations of the present study and consider its original contribution to knowledge.
- To consider the wider implications of the study for intervention and include specific guidelines for professionals who work directly with young people on the autism spectrum.
- To examine the implications of the study for other systems around the young person including Educational Psychologists.
- The chapter will conclude with implications for further research.

In the first part of this chapter, I will begin by summarising how the findings outlined in the previous chapter relate to the research questions which were introduced in Chapter one. These were:

- 1) What has been your experience of post-sixteen transition?
- 2) Have there been any factors that have had a particularly positive effect on your experience?
- 3) Have there been any factors that have had a particularly negative effect on your experience?

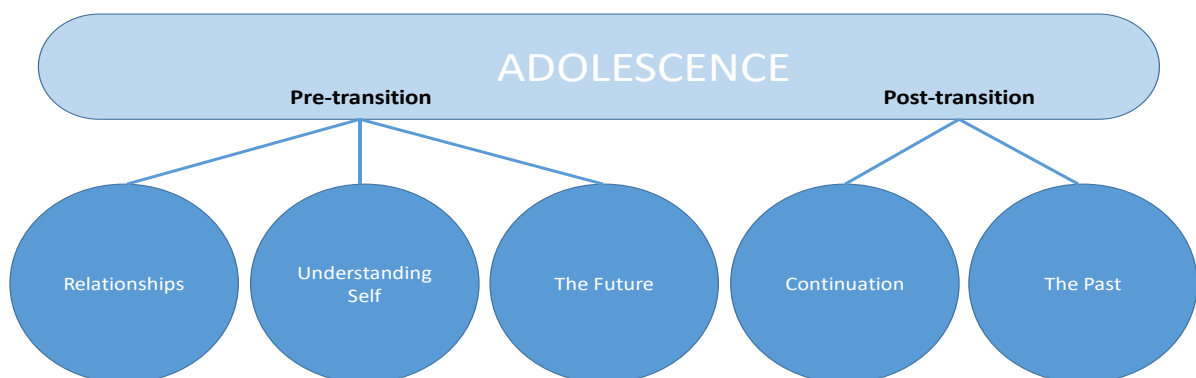
5.2. Addressing research questions

The aim of the study was to explore the experiences of the participants as they approached the end of secondary education and moved onto further education. This transition can offer significant challenges but also present new opportunities for young people (Henderson et al. 2007). I was interested to explore this from the perspective of young people with a diagnosed autism spectrum disorder, as the difficulties of transition for this population are well-documented (Wing, 1996).

The first research question was kept deliberately broad in an attempt to capture different aspects of this experience from the unique perspective of the individual participants. The second and third research questions had a narrower focus, with the intention of helping to inform the professional practice of adults supporting young people on the autism spectrum during this time.

The findings from the current study, reveal that although individual themes developed for each of the participants, there were similarities that connected the more general experiences of the participants, both prior to transition and following transition, and these have been demonstrated by the joint themes. Within the pre-transition phase the joint themes included: Relationships, understanding self and the future. In the post-transition phase, these were: Continuation and the past. The implications drawn from these findings will be discussed in this chapter.

Figure 1 – Pre-transition and post-transition master themes



5.2.1. *Over-arching theme: Adolescence*

In discussing the findings, I believe that 'Adolescence' is an over-arching theme across both the pre-transition and post-transition stages. I will discuss the main findings of the study in terms of Erikson's Psychosocial theory (1968). I believe that this theory has particular relevance to understanding the experiences of young people during this period and allows us to acknowledge the similarities and also observe potential differences between young people with autism and their non-autistic peers.

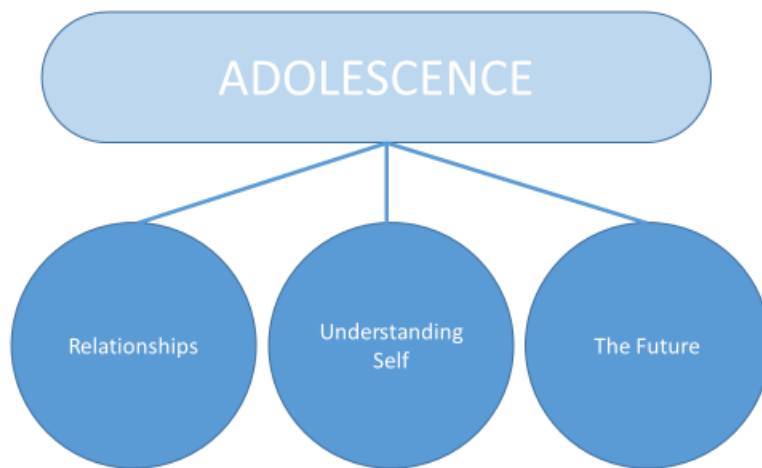
Table 11: Erikson's Psychosocial Stages

Approximate Age	Psychosocial stage
Birth – 1 year	Basic trust versus mistrust
1-3 years	Autonomy versus shame and doubt
3-6 years	Initiative versus guilt
6-11 years	Industry versus inferiority
Adolescence	Identity versus identity diffusion
Young adulthood	Intimacy versus isolation
Middle adulthood	Generativity versus stagnation
Old age	Ego integrity versus despair

Berk, L (1997, p16)

5.3 Pre-transition experiences

Figure 2 – Pre-transition master themes



5.3.1. *Relationships*

In considering the experience of the research participants prior to transition, relationships with peers was a key theme. The period of adolescence is associated with increased social interactions with peers so this theme may not be entirely unexpected (Siegel, 2013). The part that peers play in the lives of young people with autism may be different to their peers (Humphrey and Lewis, 2008) and for the participants in the study, peer relationships were often discussed in terms of the challenges, rather than the opportunities, that they presented.

Social vulnerability was evident in the participant accounts and Jack specifically referred to ‘bullies’ and relayed his experiences of ‘bullies’ in the past, who were “worse in primary”. He also expressed concerns for the future, regarding meeting new people, being unable to predict if “they’re going to be nice like some people, or extremely bad, like some people”. Tom’s relationship with more immediate peers, had the air of formality describing peers as people he can “respect and ... talk to”, which may suggest less intimate peer relationships than those that are more typical at this age.

Relationships had defined the educational experiences of Adam, providing the best and worst of times for him. He explains how friendships offered him support:

“Interviewer: Who is the biggest help in your life?”

Adam: I generally find a lot of my friends are”.

Friends presented opportunities for social activities for Adam, in apparent contrast to the experience of Tom. In understanding the relationships that challenged Adam, the brevity of his responses at times, makes the detail and impact of these difficulties rather unclear but his apparently uncompromising stance on some people is without doubt, as he explains that he “refused to get along with them”. Some writers may interpret this as an example of inflexibility that can be associated with people on the autism spectrum (Wing, 1996), but it would be a mistake to assume this, particularly in the context of Jack’s experiences.

From my perspective, as the researcher, Adam demonstrated a curiosity about the world and a genuine interest in other people. This was observed in the other participants, for example, Tom explained that “I like, with people I know, talking really”. Matt’s more settled period in education had allowed him to establish relationships with peers “by meeting new people and talking to them”, although it was in the army cadets, where he had felt less ‘judged’ and more accepted.

Significant periods of disrupted education had been a feature of the past for three out of four participants and it is reported that young people with autism are disproportionately more likely to experience periods of educational instability and exclusion (Ambitious for Autism, 2011; APPGR, 2017). On account of this, I would argue that it is reasonable to assume that this will have had an impact on the ease of relationship-forming between the participants and others within different educational settings.

To varying degrees, other people provoked strong emotions in each of the participants and for two of the participants, severe social anxiety was present, in their accounts. Jack described his feeling of threat when he was away from home:

“Cos of my anxiety, I’m always too scared to go out”.

Tom reported similar concerns around unfamiliar people. One source of anxiety which was related to travelling on the bus to college, occupied Tom’s thoughts at the end of his secondary days, and he explained that he “felt kind of scared...regarding the mornings and getting there”.

The support of other people became a joint theme in the study, but the acknowledged preference and value of this support varied between participants. The participants in the study by Acker et al. (2018) described a 'delicate relationship' to help in that they needed help to navigate a confusing social world, but they could not be sure that it would not accentuate their differences and potentially make situations worse. In the current study, it is possible that Matt's description of feeling "annoyed" by the Teaching Assistant "sitting next to me" could be interpreted in this way.

For Jack however, he had a different approach and his feeling of vulnerability was increased when adults were not available to more directly support him:

"I don't have my social worker all the time or TA's... and that's always when it gets mainly worrying".

In an apparent contradiction however, this was balanced by his belief that others lacked a genuine understanding of him or were being overly critical. At one point, Jack expressed his frustrations with his parents, exclaiming: "Stop criticising me parents". This dichotomy could be interpreted as Jack's search for self-understanding or identity, associated with this adolescent period (Erikson, 1968). In response to changes in Jack's timetable, his perception of feeling "out of control", it could be argued, is suggestive of some type of 'crisis', which Erikson (1968) uses to describe the predominant emotion for young people during the adolescent period. This is also evident in the accounts of other participants, but for each of them, is more related to different periods in their lives, when specific circumstances magnified challenges. For Matt, his time out of education resulted in him "doing silly things" and he acknowledged that secondary school, "kept him out of trouble".

For all the participants, parents played an emotionally 'containing' function. Tom's mother, for example, encouraged him to look at the "bigger picture" when he was especially concerned about a situation, which for Tom, sometimes reduced his anxieties. Parents also provided practical support during the transition period, for example, with transportation to college visits; validation of career choices and in offering advice, whether this was well-received or not. For example, Jack reported that his parents had advised him that "the internet's not always right" but Jack continued to consistently

explore online 'advice'. This choice to disregard his parent's warning may again demonstrate behaviour sometimes adopted by dissenting adolescents.

The role of parents is a consistent theme in literature regarding this population and it is generally accepted that parents continue to fulfil a significant role for longer, in the lives of young people with autism (APPGA, 2017). For Mitchell and Beresford (2014), the level of expectation of parental involvement may be too high but I would also argue that the level of parental support would feasibly vary between families (Hatfield et al, 2017).

5.3.2. *Understanding self*

For the participants in the study, there was a sense that over the passage of time new understandings had emerged, leading to increased self-awareness. As Matt explained when he was younger, he "just said before he thought" and over time realised "that if you do something good then you'll get something good back". For Jack, moving onto college meant that new 'responsibilities' had developed in supporting a friend "so she finally learns how to be independent" which led him to reflect on his loyalties to peers.

The participants in the current study, described a sense in which they felt 'different' to their peers and this had developed over time. Their assessment of this was partly influenced by observing others around them, in a way which resembled the participants in studies with similar groups (Humphrey and Lewis, 2008; Huws and Jones, 2015). There seemed to be a degree of acceptance of difference noted in the accounts of Tom and Matt, with Tom describing that "his personality" may prevent him from joining college social clubs. For Jack however, his 'strong feelings' and his observed sense of injustice relating to his past and present experiences, had not at this time, been resolved.

5.3.3. *The future*

Change and uncertainty is a feature of transition that has been associated with an increase in anxiety levels for individuals on the autism spectrum (Browning et al, 2009). In the current study, Matt disliked rapid change, but for the others, there was a fear that change may bring undesirable consequences related to new and unwelcome challenges. As Adam simply explains, "I might not like the change".

A lack of involvement in transition-planning may have further fuelled Jack's anxiety, he expressed a hope that others were not "holding back" information. Insufficient detail attached to their understanding of the course structure; 'college life' and longer-term career planning characterised the accounts of the participants, contributing to further uncertainty during this period.

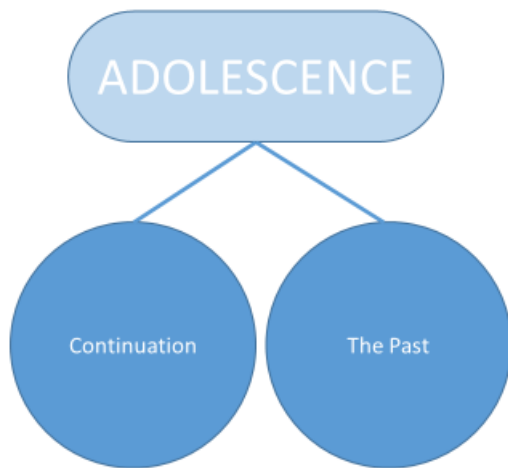
Planned transition events, including additional visits to college had been arranged for some of the participants and Tom appreciated a high number of visits, describing himself as someone who learns from "experiencing it". However, some concerns over new challenges remained.

Choosing courses at college did not seem to cause any real reported difficulties for the participants and were based on personal interests; perception of abilities; and, for Tom, broader goals related to independent living skills. A lack of paid part-time work indicated that observations of personal skills and strengths, as well as knowledge of the workplace, were based on limited practical experiences. It has been proposed that a lack of work experience places young people with autism at a disadvantage when seeking future employment (Mynatt et al. 2014; Ofsted, 2016; Hatfield et al, 2018).

Recognition of some of the opportunities that further education can introduce (Breakey, 2006) were evident in the accounts of the participants. These included: "Less days in college"; course content matched to interests; the opportunity to develop new relationships with both peers and adults, as well as the chance to engage in different leisure activities. I would agree that these aspirations fall within a 'typical' range of responses expected by year 11's anticipating their move to college (Browning et al, 2014) and indicate that the participants engaged in a level of optimistic contemplation as they approached transition.

5.4. Post-transition experiences

Figure 3 - Post-transition master themes



In organising the joint themes into pre-transition and post-transition phases, it is acknowledged that although the physical change is significant, the time period between these phases is relatively brief. A period of familiarisation to the new environment would be expected, particularly, in light of the known difficulties for this population around change (Rydzewska, 2016). The new settings however introduced both challenge and opportunity for the participants which they had, to some extent, previously predicted.

5.4.1. *Continuation*

Adolescence can introduce changes in peer and adult relationships and relationships had been a super-ordinate theme in the pre-transition interviews. There was some optimism that college would provide opportunities for the development of new relationships for Jack who was hoping to “get friends that live near”. New peer relationships which also introduced increased social opportunities were reported by Adam and a different ‘style’ of teacher -student relationship was part of Tom’s experience:

“Interviewer: Do you think your relationships with teachers are different now?”

Tom: Erm, yes, I would say so, yes, because we can like chat”.

Continuing uncertainties had impacted on Jack’s feeling of emotional and physical security within the college environment and he admitted that he needed familiar peers around him to “feel safe” within this environment. The preference for routine to support

an emotional need for predictability has been noted in literature on this population (Baron – Cohen, 2008) and continuing change and uncertainty was a source of anxiety for both Jack and Tom. Tom had been introduced to new peers at college but ‘friendships’ as such had still eluded him.

5.4.2. *The past*

It was my impression that the past experiences of the participants had an impact during their early days of college and dictated patterns of behaviour which they soon established. Jack suggested in the pre-transition interview, that he lacked confidence in his ability to ‘solve’ problems, reporting that he “pretty much never” was successful with this, within the college environment this perception seemed to continue. It is possible that this lack of self-belief may have led to an increased dependency on others, as Jack had explained previously, his anxieties increased when supporting adults were not available.

Tom reported optimistically, that he would ‘get used’ to new experiences, but elements in his past story suggested otherwise, and there was a sense that becoming conversant with new experiences, sometimes required a high personal cost. For Matt, his “wait and see” approach could also be interpreted as a reaction to the amount of change and past uncertainties in his life and may indicate that he was unable or unwilling to make predictions.

Resilience became a more obvious theme in the post-transition stage, when new challenges were presented. Jack, for example, “knew he would end up liking college” although it was clearly difficult for him at this stage and Tom was using public transport consistently which had been a huge source of anxiety previously, as Tom explained:

“I’m getting used to the buses...and ordering food in the canteen”.

Adam was required to make significant adjustments to his plans but was willing to consider the “good points” of the new college. In other studies, a lack of resiliency has been noted, for example, in managing stress (Browning et al, 2009) and relationship issues (Humphrey and Lewis, 2008) and although these were areas of difficulty for some

of the participants, the resilience observed in coping with many potentially challenging situations must be applauded.

Personal strategies and resourcefulness were developed by the participants, in response to challenging situations such as: self-talk and “finding out more information” which helped the participants to reduce anxieties. For Tom, distracting himself with his phone in busy college spaces, was proving to be effective.

Throughout the interviews the participants demonstrated contemplative and honest responses when discussing their experiences. This level of self-reflection has been observed in other studies with similar-aged participants (Dillon, Underwood and Freemantle, 2014) and this is a quality that has not always been associated with individuals on the autism spectrum (Beresford et al, 2004).

5.5. Question 1: What has been your experience of post-sixteen transition?

Table 12: A summary of the participants’ experience of post-sixteen transition

Jack	<ul style="list-style-type: none"> • Jack had mixed emotions regarding moving onto college. • He told me that he was “ready to move” to college. • He was hopeful that he could make new friends at college. • He was looking forward to meeting ‘experts’ amongst the staff who could support him with his different needs. • Jack was anxious about meeting peers who had been unkind to him in the past. • In college, there continued to be many uncertainties. His timetable changed several times, and this made him feel unsettled. • Jack was feeling especially anxious in the crowded areas of the college. He felt socially vulnerable within the college environment. • Jack wasn’t enjoying all his lessons. He felt that he was being taught things that he already knew, ie aspects of life skills lessons. • Jack had gained confidence from practical learning, including working in the Children’s Centre garden. • Jack’s walk to college was causing him some anxiety, he didn’t feel comfortable being out “in public”. • After a promising start, his relationships in college were becoming increasingly difficult, with both members of staff and peers.

	<ul style="list-style-type: none"> • Jack seemed disappointed with his post-sixteen transition, at the end of the first term.
Tom	<ul style="list-style-type: none"> • Tom had mixed feelings about moving onto college. • He was looking forward to his new course, learning independent living skills, such as cooking and cleaning. • Tom was optimistic that relationships with adults in college would be more “equal”, for example, calling teachers by their Christian name. • Tom was very anxious about using public transport to travel to college. • His sensory needs and social anxieties meant that he didn’t enjoy crowded areas and was worried about this within college. • Tom experienced some successes within the college environment. • He had become much more confident in using the buses and was managing to use the canteen, using his phone to ‘distract’ himself. • Tom was pleased with some of the cookery skills that he had learnt. • Tom’s success with using the buses had led to wider opportunities to increase his independence, for example, stopping at the shops on his way home. He had avoided this in the past. • Tom was pleased that he was able to “chat” with the teachers at college and it seemed like a different relationship to the one he had with school staff. • Tom’s work experience was a significant cause of anxiety for him and he found it very stressful, taking time off when he was especially anxious and speaking to his CAMHS therapist about it. • Tom was worried about how his difficulties with his work experience would be resolved in the future.
Adam	<ul style="list-style-type: none"> • Adam was optimistic that college would bring new opportunities. This included: establishing new friendships, meeting up with old friends, wider social opportunities and more interesting courses. • For Adam, the appearance and atmosphere of the college was important, he had especially liked the look of his chosen college. • Adam’s exam results led to a change of post-secondary plans. He enrolled on a different course and at an alternative college. Adam seemed to adapt well to this change. • Adam had met some new friends at college and gained more independence, such as walking into town. • Relationships were going well, with peers and college staff.

	<ul style="list-style-type: none"> Adam was enjoying his foundation learning course and was studying subjects that he hadn't studied before, ie Business and Childcare. He liked the practical leaning involved in the course.
Matt	<ul style="list-style-type: none"> Matt was looking forward to moving onto an IT course at college. He had a career plan in mind, wanting to work with computers, and possibly start his own business one day. He was keen to move forward with his plans. Matt wasn't sure what the differences would be between school and college. Matt had chosen a course at the nearest college but found a course there that suited him. He was prepared to "wait and see" what college would bring.

5.6. A summary of the findings: Research questions 2 and 3

Question 2

Have there been any factors that have had a particularly positive effect on your experience?

Question 3

Have there been any factors that have had a particularly negative effect on your experience?

I was sadly unable to meet with Matt to explore his views on positive or negative factors retrospectively and this was especially disappointing because I was keen to discover how his story developed.

In addressing these research questions, for ease of understanding, I have presented the findings in table form.

Table 13: Positive and negative factors associated with the participants' transition experiences

	Positive	Negative
Jack	<ul style="list-style-type: none"> • Visits to college prior to starting college. • Early relationship with his tutor. 	<ul style="list-style-type: none"> • Other students who Jack met on the visit days, further increased his social anxieties. • Lack of contact with college staff over the summer holiday meant that Jack was unable to find answers to the questions that he had, for example, regarding appropriate clothing to wear. • The transition that Jack was expecting over the summer did not take place. This meant that he felt 'let down'. • Continuing uncertainties in the early weeks of college enhanced Jack's feeling of vulnerability. • The college staff were not able to support Jack with friendship issues. • Deteriorating relationships with certain members of staff.
Tom	<ul style="list-style-type: none"> • Pre-transition visits. • Meeting new members of staff. • Being introduced to other new students during pre-transition visits. • Engaging in experiential learning prior to starting college. • The 'bus buddy' scheme that Tom had accessed over the summer holiday and the graduated approach that was used. • Tom enjoyed aspects of the induction period such as "a really cool thing" which involved students taking photographs of different places around the college to 	<ul style="list-style-type: none"> • Tom did not articulate any negative factors in his transition experience.

	support them with their orientation	
Adam	<ul style="list-style-type: none"> • Touring college premises prior to making an application. Adam's initial choice was partly based on the aesthetics of the college, because it looked like a "nice place". • "Knowing people", from previous schools, who were attending the same provision, was reassuring for Adam. • Adam felt that it was helpful to meet a Careers Advisor prior to transition, although he was unable to recall most of the conversation. 	<ul style="list-style-type: none"> • Adam reported that he did not enjoy the longer days at college.
Matt	<ul style="list-style-type: none"> • Matt valued the support of staff at his secondary school, particularly the Special Educational Needs Coordinator who he had established a positive relationship with. • Matt was also positive about the Learning Support staff in the final two years of secondary and reassured by "knowing that someone was there" who could support his career goals. 	<ul style="list-style-type: none"> • Meetings with the Careers Advisor were not helpful for Matt. She did not take account of his career interests and he "stopped going".

5.7. Findings related to the existing literature

In the following section, I will relate my findings more specifically to the current research in the area of post-sixteen transition. Within the Introductory section and the Methodology chapter, I explained that I have interpreted the post-sixteen transition phase to cover an extended period for the participants, which begins prior to the physical transition process, in the last two years of secondary when some transition-planning may take place and immediately following, and this is supported by other studies reporting on the process (Bell et al, 2017; Hatfield et al, 2018).

In considering this topic, it is very apparent that the literature that relates to this period is extensive but much of it recounts parental or professional perspectives during this time. There are also countless descriptive accounts and literature which originates from the United States where the transition process is more formalised in legislation and differs to the UK experience, in terms of its timing in the life of the young person and to a certain degree the resources that are available to support young people during this time. There are still significant gaps however in literature which describes empirical studies and particularly those that specifically focus on the voice of the young person, both in the United States, and in Europe. The range of descriptive and empirical literature related to this population in the United Kingdom is still more limited. The purpose of the current study was to contribute to existing knowledge in this research area.

Within the current study, inclusion of the voices of young people was of paramount importance to me because this appeared to be an area that has been neglected in research (Preece 2002). The nature of the autism spectrum and the social communication difficulties that are associated with it, mean that there can be a danger that young people's voices may be over-shadowed by louder or more powerful voices. I chose therefore to focus solely on the voice of the young person. The choice to base the study on post-sixteen transition was also related to the known difficulties of transition for young people on the autism spectrum and its timing within the adolescent period, which potentially increased challenges for these young people (Wing, 1996).

The 'adolescent period' often signifies increasing autonomy for young people and is described by Dan Siegel (2013) as 'filled with a sense of uncertainty by nature (p28) and "is itself a time of great transition". Experiencing educational transition within a developmental period which is already associated with some disturbance (Erikson, 1968), is particularly significant when interpreting the findings of the current study. In analysing the findings, I will continue to consider the findings with regard to psychological theories of relevance, with Erikson's Psychosocial theory (1968) being a particularly valued one during this phase.

5.7.1. Adolescence

In interpreting the findings of the current study, adolescence was an over-arching theme and although the study did not directly compare the participants' experiences with those of young people without an autism diagnosis, the impact of significant physical, physiological and psychological changes associated with puberty on all young people, cannot be underestimated. Specific differences in physiological processes during the teenage years have been noted in some young people with autism, such as: 'a compromised immune system or digestive challenges' and a greater risk of seizures than for non-autistic teenagers (Sicile-Kira, 2006, p16) and although this has not been a focus of this study, it should be acknowledged. Jack, for example, spoke of his "infection" and medical issues may have been experienced by other participants, which could have affected their perceptions at this time.

Some authors writing about young people on the autism spectrum during this period, suggest that for parents, separating the features of autism from those of adolescence can be a challenge (Nichols, Moravcik and Tetenbaum, 2009). As Nichols et al. (2009) propose, which complements my view, this may in fact be a false division, and that it is likely that the interaction of the two, makes this a particularly challenging period for some young people with autism.

Identity

For Erikson (1968) the adolescent period is a time when identity exploration becomes an absorbing task for all young people. It is generally accepted by current theorists that questioning values and plans is part of a process necessary for maturity, but state that this is more of an *exploration* than a *crisis* as Erikson described (Baumeister, 1990). Arnett (2000) proposes that in modern, industrialised societies a further stage of development which he describes as 'emerging adulthood', distinguished as "relative independence from social roles and from normative behaviour" (p469). He does concede however, that culture influences structure and sometimes limits the extent to which young people in this age period are able to use these years for independent exploration. In considering the experience of young people with autism, I would argue that cultural and societal

restrictions and perceptions of normality, continue to create additional barriers for positive identity exploration in adolescence and beyond.

Erikson (1968) describes the negative outcome of the adolescent stage as *Identity diffusion* and this suggests that for some young people they may appear 'shallow and directionless' (Berk, 1997, p438) because of earlier unresolved 'conflicts' or the restrictions that society has placed on their choices. For Erikson, this results in adolescents being unprepared for the psychological challenges of adulthood (Berk, 1997, p438). In assessing the experiences of the participants during this period, there was evidence of some 'direction' during this transition period and Matt seemed very confident in his decision-making, for example, he "looked at all the courses and decided that it (IT course) was the best one". In my mind however, there may be a greater risk of negative outcomes, if difficult experiences continued to feature in the lives of the participants.

In respect of Erikson's theory (1968), it is possible that the restrictions that are placed on young people with autism, by society, which includes: gaps in the understanding of the autism spectrum (APPGA, 2017), a lack of effective inclusion (Chown and Beavan, 2012) and limited accommodation of their needs (Breakey, 2006; Beardon, 2017), will place them at greater risk of identity diffusion as they move through adolescence and into young adulthood.

In the following section, I will present the main findings that have emerged from the individual and joint themes within the study, and support the current literature relating to the experiences of young people with ASD during this period. I will then follow this with a discussion of the findings that are more distinctive to the study.

5.7.2. Findings which support the current literature

Social and emotional wellbeing

An increase in mental health difficulties for today's adolescent youth has been a significant societal concern (Weare, 2015). For two of the participants in the study, heightened levels of anxiety were reported in the pre-transition and post-transition phases. As Jack reported, in response to moving learning groups within college:

Jack: "I think that's another reason why I feel so out of control at the moment".

And for Tom, in the early days of his work experience:

Tom: "Erm, too stressful...I can only tolerate so much stress in a day".

Many studies have identified that there is an increased risk for individuals on the autism spectrum during this time (Browning et al, 2009). In common with other studies regarding this population, small sample sizes and the tendency for studies to focus on particular aspects of mental health, may be a limitation (Browning et al. 2009). Personal accounts have, however supported findings. For Grandin (2005) anxieties were much more pronounced during the adolescent period but she is not easily able to explain the reasons for this.

Puberty arrived at fourteen, and nerve attacks accompanied it. I started living in a constant state of stage fright, the way you feel before your first big job interview or public speaking engagement. But in my case, anxiety seized me for no good reason (Grandin, 2005)

For the participants in the study, their anxieties covered a range of issues, including social vulnerability, social communication issues, fear of bullying, using public transport and concerns related to change and uncertainty. There was also a sense, particularly in talking to Jack and Tom, that they experienced a persistent level of anxiety within educational environments but, as the findings indicate, some new anxieties also evolved during the transition period. These are all areas of concern expressed by other young people on the autism spectrum as indicated in a variety of literature (Grandin and Panek, 2014; Browning, Osborne and Reed, 2009; Hebron and Humphrey, 2014; NAS, 2018). Greater levels of anxiety have been noted directly relating to aspects of transition, in studies which compare young people with autism to their non-autistic peers (Browning et al, 2009) and also in studies, that indicate that the range of challenges within educational environments increase the risk of mental health difficulties for this population (Adreon and Durocher, 2007; Baric et al. 2017).

For two of the participants there was less evidence of heightened levels of anxiety during this transitional period but in the context of studies which identify the prevalence of

‘masquerading’ (Carrington and Graham, 2001), it is possible that this was an emotion that was being effectively concealed.

Adolescent challenges for young people with ASD

In addressing further challenges that could potentially present during this period, I believe that it is relevant to discuss these with reference to the established writings of a respected figure in the field. Dr Lorna Wing, social psychiatrist and one of the ‘founding parents’ of the National Autistic Society (Baron-Cohen, 2008, p21) was one of the first to question the prevailing view of autism as a rare disorder and stated that it should be recognised as a ‘spectrum disorder’. Wing (1996) considers that the period of adolescence is not a ‘period of disturbed behaviour’ for all young people on the autism spectrum, but for some it is. She suggests that the main areas of difficulty include:

- Wanting friendships and sexual relationships.
- Desire for independence.
- Increasing awareness of disability.
- Pressure of exams at school (p162)

Challenges within these broad areas have been illuminated in research relating to this population (Portway and Johnson, 2003; Humphrey and Lewis, 2008). I will use these general areas as headings within the chapter and to introduce a discussion on the experiences of the participants in the current research.

Wanting friendships and sexual relationships

This is a consistent theme in literature regarding individuals with autism, throughout the lifespan, but the adolescent period is recognised as being particularly challenging. Experience of difficult relationships have been described in personal accounts (MacLeod and Johnston, 2007) and research studies (Carrington and Graham, 2001) with vulnerability to bullying also referred to in a wide range of literature (Jackson, 2002). The type of ‘bullying’ for one participant in the current study became more verbal in nature and less physical over time, which is a pattern supported by other literature (Humphrey and Lewis, 2008). Social exclusion as a form of ‘bullying’ (Beardon et al. 2009) and resulting social isolation during this period is not specifically mentioned in the accounts of

the participants, but the image of Tom regularly sitting alone in the college canteen, is a reminder that this can be part of the experience for some young people with autism. Social isolation is apparent in research with this age group however and also in adult accounts (Portway and Johnson, 2003; Beardon and Worton, 2017).

Literature that more specifically refers to the adolescent period, rejects the claim that young people with autism are less interested in peers and confirms that these young people are keen to 'fit in' (Sicile-Kira, 2009; Jackson, 2002).

For Beardon and Worton (2017) 'fitting in' is not only an adolescent preoccupation and relates to an ongoing quest for acceptance.

It seems so obvious that accepting someone for who they are would be hugely important for anyone, but how many people with Asperger's syndrome are afforded that consideration (Beardon and Worton, 2017, p80).

For the participants in the study, a genuine interest in peer relationships was present within their accounts, but a relationship between this and a quest for a sense of belonging (Schall et al, 2016) or a perceived vulnerability (Jackson, 2002) is unclear. The study by Carrington et al. (2003) demonstrated that for their participants there was a lack of comprehension regarding the "nature and reciprocity of friendship" (p216) but in the current study, there is evidence that, for at least two of the participants, Jack and Adam, they had emotional attachments to friends. It is possible that the participants in the current study differed in their interpretations of friendship, but this was not explored to any degree by the researcher. I would argue that 'friendship' can be experienced in different and distinct ways by individuals (Henderson et al, 2017).

A lack of peer relationships, however, can be a concern for supporting adults and a consistent request has been made by parents, that buddying or befriending schemes would be a valuable resource (APPGA, 2017; Hatfield et al, 2017). This does not appear to have been effectively addressed in practice, according to research (Mitchell and Beresford, 2014).

Informal and formal romantic or sexual relationships were not a particular theme in my study, but do form, for at least two of the participants, part of a plan for the future.

Studies which relate to the longer-term outcomes for adults in the area of future relationships are mixed in their findings but are relatively consistent in that very low numbers of adults with autism have been reported to be in long-term relationships and this is a significant concern (Howlin, 2004; Hendricks and Wehman, 2009; Howlin and Moss, 2012). Interpretation and comparison of outcome studies can offer many challenges however, in that they have varied widely in their “data collection methods, differences in the characteristics of their cohort and inconsistent assessments” (Sosnowy, Silverman and Shattuck, 2018, p29). This was also supported by Levy and Perry (2011) in their review of ‘outcomes’ literature and they propose that studies do not represent the diversity of individuals on the autism spectrum, as is a feature of much literature in this area.

Particular difficulties for young people with autism in managing more intimate relationships are however well-documented through personal accounts of individuals (Portway and Johnson, 2003; Muller et al, 2008). Romantic relationships may add another layer of confusion to the subtleties and nuances of social interaction for this age group (Jackson, 2002; Dewinter, Parys, Vermeiren and Nieuwenhuizan, 2017).

A desire for independence

The ‘desire for independence’ as highlighted by Wing (1996) is a theme associated with the adolescent period and this has been directly related to the increasing importance of peer relationships both in terms of a time and emotional commitment (Siegel, 2013). As indicated in the study, not all young people on the autism spectrum experience the same level of interaction or connection to peers as non-autistic adolescents. The definition of ‘independence’ is however, much wider than this and can be subject to different meanings within studies (Eaves and Ho, 2008; Manzoni, 2016).

In a study by Barrow (2013), on post-sixteen transition experiences for young people with Autistic Spectrum Disorders, her participants assessed that independence was related to managing alone and without the help of support services. For Barrow however, she felt that skills in self-advocacy were essential requirements for ‘independence’ and stated that further studies were required to explore what independence means for those on the autism spectrum.

In the current study, the participants related post-sixteen transition to an increased level of independence but their interpretation of this varied. Jack envisaged a future which involved continued support from carers whilst living separately from parents in a long-term relationship, whereas Tom, described 'independence' in terms of acquiring skills to support him to manage the functional aspects of adult life, such as "learning to cook" and launder clothes but expressed no desire to marry.

For some writers achieving the markers of independence such as living separately to parents, is complicated by the social, economic and political circumstances that can make this a challenge for all young people today (Rydzewska, 2012; Henderson et al. 2007). I would agree with Manzoni (2016) that "we need to stop thinking of independence as a binary concept, as either 'independent' or 'dependent' ...it's more complicated than that".

Some studies have identified that parents of children and young people with autism are eager that their offspring develop 'independence' through learning key life skills (Beresford et al, 2007; Tobias, 2009) and adopting adult roles and responsibilities (Anderson, Sosnowy, Kuo and Shattuck, 2018). Many studies indicate that parents continue to fulfil a key role in both practical and emotional support during adolescence (Mitchell and Beresford, 2014; Hatfield et al, 2017). In the view of some professionals, as reported by Anderson et al. (2018) their continued involvement hinders young adults in developing life skills and greater independence.

For some writers the debate is more effectively positioned by relating it to the aspirations of young people with autism and studies generally confirm that young people with autism have similar aspirations to their non-autistic peers (Beresford et al. 2007; Camarena and Sarigiani, 2009; Sosnowy et al. 2018). The participants in the study by Sosnowy et al. (2018) however expressed only "a general sense of their goals for the more distant future" (p33), indicating a lack of detail in their plans. In the current study, this was also apparent in a detachment from longer-term career goals, as Tom described his "career calling" to be an Engineer as a "very long-term goal", although I would argue, that a lack of clarity around long-term career goals is not unusual for this age group (Henderson et al, 2017). In terms of more general aspirations, more transparency was evident, and these broadly matched those of non-autistic adolescents.

Increasing awareness of disability

In assessing factors related to the identity exploration of the participants in the study, it was apparent that negative constructs were part of their self-perceptions and these were described in a similar way to the participants in the study by Humphrey and Lewis (2008). Tom, for example, spoke about his “bad habits” as well as his “bad memory” and Jack quoted a list of perceived inadequacies, which were related to the features associated with his autism:

Jack: “...and I don’t think about other people’s emotions and the tone of my voice”.

Although the word ‘disability’ was used by only one of the participants, it was evident that their autism caused them to feel different to their peers. It is unclear within the confines of a time-limited study however, whether this had increased over the course of adolescence (Wing, 1996, p162).

In interpreting the experiences of the participants, social comparison processes were demonstrated (Huws and Jones, 2015; Hebron and Humphrey, 2014). In the study by Huws and Jones (2015), participants compared themselves directly to others, which for the majority had a positive effect on their self-concept and self-esteem. In the current study Jack compared his more effective ‘life skills’ to his immediate peers but, in the majority of his account he made downward social comparisons to a wider group of peers and this is more in line with the participants in the studies by Hebron and Humphrey (2014) and Acker et al. (2018).

Some of the participants in the study by Huws and Jones (2015) reported that increased maturity and self-awareness had meant an attenuation in their ‘traits’ associated with autism and this is comparable to the accounts of Tom and Matt, as Matt explained how he “grew up” and Tom stated that he had become aware of his “past mistakes”. An alternative interpretation proposed by Shakespeare (2013) however, is that this is a ‘normalising strategy’ that people with ‘hidden disabilities’ may use to appear more ‘normal’. Although this is difficult to verify within the context of the study, some elements of the participants’ accounts, could be interpreted in this way. Some of Jack’s honest

reflections were related to his perception of normality, “wanting to get back to what a normal person might be”:

“Interviewer: And how does that make you feel...that you might need more help than some people?

Jack: Not normal...I’m not normal because I need more help”.

‘Masquerading’ or masking difficulties is a strategy identified as being used by young people with autism, particularly those diagnosed with Asperger’s Syndrome or high-functioning autism (Carrington and Graham, 2001; Carrington et al, 2003; Muller et al, 2008). It can be interpreted as a device to hide their difficulties and this may support the view of Shakespeare (2013) that, in their eyes, difference or disability is socially undesirable.

In situating this study in terms of the discourse around perceptions of normality, adult writers, who identify themselves as being on the autism spectrum, suggest that the language around autism, is used on ‘a daily basis’ to “label others in stereotypical and prejudicial ways that leads to their marginalisation” (Richards, 2016, p1301). ‘Deficit’ thinking related to the ‘medical model’ (Davis and Watson, 2001) is apparent in the participants accounts and they identify themselves as ‘different’ by the label that they have been assigned (McKenzie, 2013). This was very apparent in Jack’s account. The implication of labelling for Oliver (1990) is that it can create “a patronising relationship between professionals and people with disabilities” (p23).

An alternative to the discourse of dependency, deficit-thinking and negative social comparisons, I would argue, is one which focuses on strengths, abilities and the resiliency of the participants, which were clearly apparent in their accounts, but not explicitly acknowledged by them. I would argue that the concept of self-efficacy, as described in Bandura’s Social Learning theory (1977) is an important construct which has value in supporting young people with autism. I believe that this theory has some relevance when interpreting some of the behaviours of the participants.

Experiences that Tom was particularly keen to share were those that he had initiated himself, such as visiting Asda and giving a donation for a poppy. For Jack, he also

recognised that he had skills in “making things” and “being creative”. Jack’s most positive experiences at college, that he recalled, were practical skills that he had gained in the Children’s Centre garden and he was able to recognise that this had encouraged him to feel confident in his abilities. Hatfield et al. (2018) have also related the concept of self-efficacy more directly to supporting transition processes and suggesting that young people will gain confidence in their abilities by being more actively involved.

Pressure of exams

There is a recognition that leaving secondary school is an anxious time for many adolescents and that this is partly due to its concurrence with an important exam period. Some studies note that there are similarities in the concerns of autistic and non-autistic adolescents at this time, which included academic stresses (Acker, Knight and Knott, 2018). The pressure of exams (Wing, 1996, p162) was directly referred to by Jack but less explicitly by the other participants in the current study, although they all spoke in more general terms about the exam period.

The following section relates to the more distinctive findings, that emerged from the individual and joint themes, within the study.

5.7.3. Findings which are more distinctive to the current study

The impact of past experiences

Adolescence, according to Erikson (1968) is a time of increased focus on identity and individuals may explore a variety of new roles. The developmental nature and the impact that each stage has on the next, in Erikson’s theory, suggests that the previous social encounters of the participants should also be considered when interpreting their experiences.

Social relationships were a key theme in the current study and changes over time in the nature of relationships with both peers and adults was evident throughout. Relationship concerns however, were not exclusively a feature of the teenage years for the participants and had been present at different points in their lives, as Jack’s description of the ‘bullies’ at primary school reminds us.

It is proposed in some literature that children and young people with autism experience lower peer acceptance overall and a difference in peer dynamics (Dillon et al, 2014). Some studies suggest that they are less interested in friendships than their non-autistic peers (Huws and Jones, 2010), a conclusion that has been questioned by the findings in the current study. These studies, however, may also fail to adequately appreciate the cumulative effect which challenges relating to social communication and interaction may create for individuals on the autism spectrum. These are clearly evident in Jack's descriptions of his perceived vulnerability within the further college environment, a perception which was influenced by his past negative experiences.

Jack's plea that the transition course that he had been promised would help him to "get back to what a normal person might be" and support his social understanding, appeared to be an ongoing quest. It is likely, for Jack, that past experiences would have impacted on his motivation to engage in relationships, if he felt that there was a risk of making social 'mistakes' (Muller et al, 2008) and it is my impression that this was also part of Tom's experience.

Tom appears to have adopted a more cautious approach to peer relationships which may have developed in response to his 'annoyance' that "some people criticise me". Similar to Jack, Adam's apparent preoccupation with relationships could be interpreted as a desire to follow the social norms that he had observed within past educational environments (Schall et al, 2016).

The past had also impacted on the educational opportunities available to the participants. For three of them, periods of educational instability meant that they experienced an additional disadvantage when moving into a further education environment, and although this has been recognised within wider literature (APPGA, 2017), it is under-acknowledged in research on the post-sixteen transition period. The academic and social disadvantage attached to this, should not be under-estimated. As Tom described after his return to school:

"In the end, I was able to accomplish entering exams...Maths and English Language".

When compared to an average student, this reduction in exam courses, would have had a significant impact on the course choices available to him within college. In broader terms it could potentially have had an impact on the academic assurance and also the social confidence of the participants, as they moved into a new educational environment.

The observation that young people with autism may experience more negative views of themselves (Humphrey and Lewis, 2008) is supported within the study but the ongoing impact of this, is also apparent. For Tom, he clearly identifies that his “past mistakes” led him to re-evaluating his behaviours and conclude that his “bad habits” needed to be altered. This conclusion resulting from Tom’s past experiences, I would suggest, has significant implications for positive identity exploration and development.

Although some studies have related some future concerns to past negative experiences (Bell et al, 2017), the current study may further increase our understanding of the wider implications of the past on self-perceptions and self-confidence.

Communication of individual needs

The features associated with autism, which include potential difficulties with social communication and interaction, is an area that is well-documented and has been explored in past studies (Baron- Cohen, 2008; Acker et al, 2018) with some studies predicting the possible challenges within a further education environment (Roberts, 2010). I would argue that the findings in the current study add further information to how these areas of difficulty may be enhanced by transition and observed in the new environment.

An example highlighted in the study was the participants’ perceived inability to share their concerns with adults within the further education setting. Jack described his communication challenges in detail in both his pre-transition and post-transition interview. His lack of confidence in communicating his views was further enhanced by his more general social anxieties, as he explained that he was “too scared” to tell staff about a wider range of concerns, which resulted in an increase in anxiety for Jack.

In his post-transition interview, Tom also shared his worries relating to his work experience, but he failed to share this with college staff and responded by taking time off.

Tom reported that he was aware of “student support services” and had developed a positive relationship with his tutor, but chose not to share his concerns with them, discussing them instead with his CAMHS therapist.

There is an implication in the stories of Jack and Tom, that trusting relationships may take time to develop, and at this early stage of college life, these were not available to them. The critical issue of trust in relationships with adults, for young people on the autism spectrum has been acknowledged in research (Bell et al, 2017). The current study however, may help us to further understand the implications when this is not available and additionally confirms that communication challenges may be further enhanced within this environment.

Parental influence

Literature relating to the post-sixteen transition period has identified the important role that parents fulfil in the lives of their young people with autism, in advocating for their needs within education (Tobias, 2009), as well as in continuing to provide practical and emotional support (Mitchell and Beresford, 2014) and the findings of the current study support this. The findings further illuminate however, the complexity of this relationship as children with ASD pass through adolescence.

Within the accounts of the participants, there is a tension between a desire for independence and a perceived ‘need’ for parental support. The participants in the study all spoke of their vision of greater independence but in their stories the ‘presence’ of parental influence was clearly visible, in the practical and moral support offered to them, and examples quoted by the participants add further to our understanding. For example, Jack’s explanation of his parents’ remarks warning him that the “internet’s not always right” and Tom’s mother encouraging him to see “the bigger picture” may imply that these parents continued to fulfil a role in attempting to reduce specific anxieties.

Social anxieties leading to hyper-vigilance within public spaces is also clearly a significant feature in the lives of Jack and Tom and this supports their view that home is a ‘safe’ place (Hill, 2014). A ‘push and pull’ effect appears to be at play for the participants, in desiring an increased level of independence whilst relying, to some degree, on the

reassurance of parents. The particular challenges related to adolescence and the transition period, may have further enhanced the apparent tension within these relationships at this time, which is also observed within this research.

Wider support networks

The individual differences between people who share an ASD diagnosis is an established theme in research (Hatfield et al, 2018). The current study adds further to this perception, and the contrasting attitudes of the participants towards wider support as they move into the post-sixteen environment is visible.

For the participants, their experiences at the time of transition were related to differing degrees of dependency on others. For Matt, he had valued the presence of school support staff in promoting his goals, but in moving forward, there was a sense that he was optimistic in believing that he would no longer require this, for example, in reference to transition support, he reported that he “didn’t need it anyway”. Tom described that he might need a “guiding hand” which may be interpreted as a more discreet form of support, available as required. This was in apparent contrast to Jack whose vision of the future included a wider adult support network.

The disparity in their views may be related to a number of factors which appeared to include: a perception of their own vulnerability as well as an assessment of their personal resources. The differences between the participant accounts confirms that person-centred approaches are critical (Breakey, 2006) but additionally, it also affirms that a deeper level of understanding or a more holistic approach is required. In my view, this should include assessing the current position of the young person, in terms of acknowledging their perceptions of personal strengths and resources, as well as gaining a wider appreciation of factors that may have influenced this.

The following sections relate to the more general themes that have been observed in the current study, as well as within a wider range of literature, that refer more directly to transition processes and the further education environment.

5.7.4. The transition period

Transition processes

In considering the transition period for young people on the autism spectrum, much of the literature supports the view that transition processes are failing young people with autism in not accommodating their unique and individual needs (VanBergeijk et al., 2008). A consistent call for more effective transition processes has been a feature of literature within this area (Hatfield et al, 2018; Hendricks and Wehman, 2009; Mitchell and Beresford, 2014) as well as by advocacy groups (Ambitious About Autism, 2011). However, there is still limited research which confirms the features of an effective transition (DfE, 2015).

It is interesting that the participants in the current study did not attend their transition-planning meeting and the reasons for this are not clear. It has been noted that young people with autism are the least likely group of young people with additional needs, to attend their transition meeting (Griffen, Taylor, Urbano, and Hodapp, 2014; Hagner et al, 2014) but there does not seem to be a clear understanding of the main reasons for this.

There is a limited amount of literature that focuses on transition to further education college and more than involves transition into employment (Hendricks and Wehman, 2009) or considers post-secondary education alongside other 'outcomes' (Anderson et al, 2018). Hagner et al. (2014) attempted to identify strategies, that they believe, support participation. These include individualized preparation for meetings and longer-term activities to create rapport between facilitators. In the current study however, very little involvement was described by the participants, in any elements of transition planning. The importance of a longitudinal process for transition which begins prior to secondary school is a consistent request in research (Baric et al, 2017; Held et al, 2004), as well as consideration of the unique features of transition to further education college (OECD, 2011). Neither of these appear to have been part of the experience of the participants.

Transition activities

One aspect of transition planning which is consistently supported is the need for young people with autism to achieve a clearer understanding of future career possibilities (DfE,

2014; Ambitious for Autism, 2011) and that these should be aspirational (DfE, 2015a, p25). Activities which support knowledge of 'real' working environments have also been encouraged and opportunities for practical work experience provided (DfE, 2014a; AET, 2018). For the participants in the current study, although they had identified a career area of interest, knowledge of a route to securing this, was missing in their accounts. There was little sense in the participants' accounts, that their career-planning was related to future financial independence and no real evidence that they had received any support to fully appreciate the relationship between the two.

Positive factors supporting transition from school to college, for the participants in the study by Mitchell and Beresford (2014) included the support of practitioners and specific forms of help, such as careers advice. Careers advice however, had minimal benefit for the participants in the current study. This may support the argument made by Mynatt et al. (2014) that the complex needs of students with Asperger's syndrome, merits an approach that considers their specific needs. Inadequate and insufficient careers support in transition-planning for young people with a range of additional needs, was noted in observations made by Ofsted (2016).

Participants in the study by Mitchell and Beresford (2014) also appreciated specific forms of help and one participant was involved in a 'bus buddy' scheme to support him with using public transport. In the current study, Tom also had access to a similar programme which had been a success for him:

"It was good because they started off as me going to the bus stop, then they started for me to go on the bus and get the ticket and go to...the...college".

Overall, however, there is a lack of consensus on the optimal content for a transition programme but some agreement on important elements of it, including: the involvement of the young person throughout the whole process and the importance of person-centred processes (Foundation for People with Learning Disabilities, 2017; Held et al, 2014); the effectiveness of additional visits prior to transition (Bell et al, 2017); access to specialist advice (DfE, 2015a); the necessity of a co-ordinator for the transition process (Mitchell and Beresford, 2014), general agreement on the need for some parental involvement (Breakey, 2006) as well as the importance of a clear plan with scheduled meetings and

formal documentation (Hatfield et al, 2018). A lack of formal transition processes, in general has been a more typical experience for young people reported in qualitative studies (Bell et al, 2017) and a consistent request for inclusion of processes that support the young person's development of social and interpersonal skills, over this time, have been advocated. In practice there is little evidence to suggest, that this has been regarded (Bell et al. 2017; Chown and Beavan, 2012; Mitchell and Beresford, 2014).

5.7.5. Life in further education

Course requirements

There was little scope within this study to explore in any detail the specific requirements of individual programmes of study and this is an under-researched area (Adreon and Durocher, 2017). Certain features that have been associated with difficulties within a further education environment, such as: information processing delays and executive functioning difficulties, as noted in a range of other studies (Adreon and Durocher, 2017; VanBergeijk et al, 2008) were not noted as problematic for the participants. This may in part be due to the fact that their courses were at a relatively early stage and any potential academic issues may not have fully emerged at this stage.

Within a college environment many of the 'advantages' that were in place at school, in terms of individualised support, appeared to have been lost when the participants became part of a larger group of foundation learners. Within this environment it was unclear how the needs of the participants relating to their autism, were being accommodated. There appeared to be a need to adapt to new roles related to course expectations which resulted in significant difficulties for two of the participants. For example, in my view, Tom's work experience assumed a level of social confidence and competence, which he seemed ill-equipped for, at that time. Jack's plea that he did 'need' support, in his view, differed to the perception of college staff, that "Jack seems perfectly fine".

A lack of appropriate educational pathways has been noted in a range of literature for young people on the autism spectrum (Ambitious for Autism, 2011) and this is supported by the findings in the study. The foundation level course which the participants enrolled on, provided a number of general courses, some of which were far from their original

areas of interest. For example, Adam's course required him to complete modules in business and childcare, whereas he had originally hoped to study a course in 'Media' and there was little evidence of secure plans for a work experience placement related to his interests. A lack of meaningful work experience on courses for high needs learners was noted by Ofsted inspectors and this related to FE provision across the country (Ofsted, 2016).

Concerns have been raised about the limitations of foundation learning with "many unhappy about what it achieves in practice" (Ambitious about Autism, 2011, p13) and as acknowledged in the report by Wolf (2011) the accreditation of qualifications "which fit you to do nothing but take more qualifications". Educational reforms introducing 'study programmes' to offer more flexibility for learners do not seem to have had a specific impact on the experience of the participants (DfE, 2018b). Although the participants acknowledged some benefits with this style of learning, it was not abundantly clear, how their study programmes related to their longer-term career aspirations.

Disabling environments

It is acknowledged that some progress has been made in the knowledge and understanding of the impact of autism for individuals within educational environments (AET, 2009) but there are still significant gaps across educational establishments (APPGA, 2017). Particular concerns remain within the mainstream further education environment (Beardon, Martin and Woolsey, 2009; Chown and Beavan, 2012; Camarena and Sarigiani, 2009) but within specialist educational provision this has been less of a concern (Williams, 2007). In my opinion, these findings were supported, to some degree, by the accounts of the participants in the current study. For example, Jack's apparent need for routine and predictability to support his emotional wellbeing had not been sufficiently addressed within college and, in my view, the management of Tom's café work experience seemed to indicate some gaps in staff understanding regarding the extent of his social anxiety.

The disabling effects of some current educational environments have been identified in literature (Humphrey and Lewis, 2008) and the high level of interaction, communication and flexibility required, as well as the sensory demands of the environment can be a source of difficulty for individuals on the autism spectrum (Baron-Cohen, 2008).

It could be argued that these are all increased in a further education environment, which contain a greater number of students, are physically larger with a resulting higher level of sensory information, as well as students being involved in generally less structured study programmes across the week. The interaction of sensory difficulties and social anxiety were mentioned by the participants in the current study. Tom spoke of the “crowded canteen” where he would automatically resort to his phone to ‘distract’ himself and Jack also explained his feelings when he is in crowded areas of the college and there is a risk that others may approach him:

“Interviewer: So how does that make you feel?

Jack: Just pretty tense, and I don’t know at all what to say.”.

Similar sensory and social challenges have been observed in other studies (Bell et al, 2017). The degree to which sensory sensitivities are experienced within educational environments may be under-acknowledged in practice and research (Bogdashina, 2003) with relatively recent inclusion in the diagnostic criteria for ASD (APA, 2013). Although there had been some effort to prepare the participants for the new college environment in the current study, it was evident that in some areas, they were ill-prepared.

Wider questions around inclusion and acceptance are raised by a lack of accommodation of their needs and the degree of inflexibility noted within educational environments, in general.

Adults on the autism spectrum maintain that the goal of education should not be to ‘change their way of being’ to make them into typical individuals but to acknowledge and appreciate their differences and create an environment in which they can thrive (AET, 2018, p79).

I would argue that the implication of ‘masquerading’ as observed in young people with autism (Carrington and Graham, 2014) is that within an educational environment the young people did not observe that their differences were accepted or valued (AET, 2018) in a way which promoted effective inclusion (Norwich, 2006).

A partnership approach

Breakey (2006) advocates a person-centred approach in meeting the needs of young people with autism, with practices that promote a greater sense of self-efficacy in students. This is partly in response to a recognition of the broadness of the spectrum. She also acknowledges that for some in the further education sector, higher academic ability equates to less 'need', but this is an assumption that Breakey (2006) negates. In the current study, the two participants who appeared to be experiencing greater challenges within the further education environment, had received different original diagnoses, which seems to support the basic premise made by Breakey (2006). Research which focuses on the subset of young people with a diagnosis of Asperger's Syndrome or high-functioning autism also refutes the assumption that those with these diagnoses will require less support (Connor, 2000).

Breakey (2006) recognises the importance of working in 'partnership' with parents in this environment. For Howlin (2005), parental support is particularly important when young people first attend college, regardless of their intellect.

few students with autism...will have acquired the social competence or level of independence required to survive when they first enter college. To expect them to be able to cope without support from their families is to deprive them of a vital backup system and to deprive college staff of a valuable source of information (Howlin, 2005).

This may appear to be an overly pessimistic view, particularly in acknowledging the success of the participants in some aspects of college life but, with knowledge of the importance of the relationship between the participants and their parents, I believe that the opinion stated by Howlin (2005) has merit.

The current study, as supported by other research (Bell et al, 2017; Connor, 2000), also indicates that a common language is possible between young people with autism and adults. I would argue that this confirms that access to supportive relationships, prior to and during this transition period, will be a valuable resource for these young people.

It is also important to explore the strengths and limitation of the current study and the implications for further research. I will now consider these areas.

5.8. Strengths of the study

Qualitative research which gives a voice to young people with autism during the post-sixteen transition period has been neglected in research and the views of parents and professionals have often taken precedence (Hatfield et al. 2017). The aim of the current study was to address this to some extent, by focusing solely on the voice of the young person and acknowledging that seeking their views may be key to the success of the process (Milton, 2016). The study outlined shortcomings in the transition process and identified communication barriers which meant that the unique needs of young people were not always being addressed within the further education environment.

The idiographic focus of the study provided an exploration of the unique perspective of each individual. The use of semi-structured interviews allowed the participants to express their views and meant that, to some degree, they could influence the direction of the interview. Other studies which have used questionnaires or surveys to collect data, have sometimes resulted in a confused understanding of the participants intention (Beardon et al, 2009).

A number of studies have focused on gathering information from young people, by using a variety of methods, such as online surveys or interviews, where a supporting adult is also present (Hatfield et al, 2018; Barrow, 2013). In this situation, it is not always clear if the young people's views have been influenced by others. The current study more clearly represents the view of the young people.

The ages of participants in some 'transition' studies can also vary, with some studies combining participants from pre-transition and post-transition phases (Mitchell and Beresford, 2014; Hatfield et al, 2018). In the current study, the chronological age of the participants and their school year were the same, which makes direct comparison more meaningful.

There are similarities and differences in the experiences of individuals across the autism spectrum and this is acknowledged in the study and supported by the findings. The participants received a range of diagnoses which have now been included in the wider category of Autism Spectrum Disorder (APA, 2013). Many studies regarding transition have focused on a subset, such as young people with Asperger's Syndrome or High-

Functioning Autism (Mitchell and Beresford, 2014). The current study therefore contributes to the evidence base of qualitative studies related to experiences of individuals across the spectrum.

5.9. Limitations of the study

There is a lack of clarity in methods which most effectively promote the effective participation of young people with autism in research (Harrington et al, 2013) but trusting relationships established over time are effective in engaging these young people in more general terms (Mitchell and Beresford, 2014). The constraints of the time available within doctoral research meant that although I was able to meet participants prior to the pre-transition interview, additional visits may have encouraged participants to share more of their thoughts and experiences.

In discussing positive and negative factors in the transition experience of participants, it is possible that dividing the transition period more clearly into periods of time, may have supported recall. As noted previously the questions used did not precisely match the written questions and it is possible that any re-phrasing may have altered the understanding for the young person.

There is a gender imbalance in the study and although this may represent the gender imbalance in diagnosis, females with autism may have had very different experiences. The study was also based on a small sample and the findings cannot therefore be generalised to the wider population of adolescents with autism. There was also a sampling bias in the study, in that participants were identified through the Special Educational Needs Co-ordinator. This meant that only those known to the learning support department were approached.

The two-part structure of the study meant that the timescale between interviews was relatively short. The nature of the autism spectrum suggests that it may take longer for young people with autism to settle into a new provision than their non-autistic peers. A longer time period between or additional visits may have resulted in different experiences for the participants.

In further assessing the post-transition stage of the process, a further limitation may have been that in following up topics from the first interview, I was unintentionally influencing the direction of the second interview. The themes that followed from this, therefore I have potentially had a greater hand in. The loss of the fourth participant may have also had an influence on the way that post-transition themes developed.

The participants had different diagnoses, but as predicted by influential figures in the field, there were some common areas of need (Wing, 1996; Baron-Cohen, 2008). Within the study, there was no consideration given to the significance of co-occurring conditions and these may have been a factor in the experience of the participants (NAS, 2018). Research into the impact of co-occurring conditions during this developmental stage, may help to illuminate this issue further.

Ongoing research into different aspects of autism and developments in neuroscience are further adding to our understanding of autism (Baron-Cohen, 2008). My knowledge of current research is therefore limited to the resources and knowledge that I had available to me, when conducting this study.

5.10. Wider implications for intervention

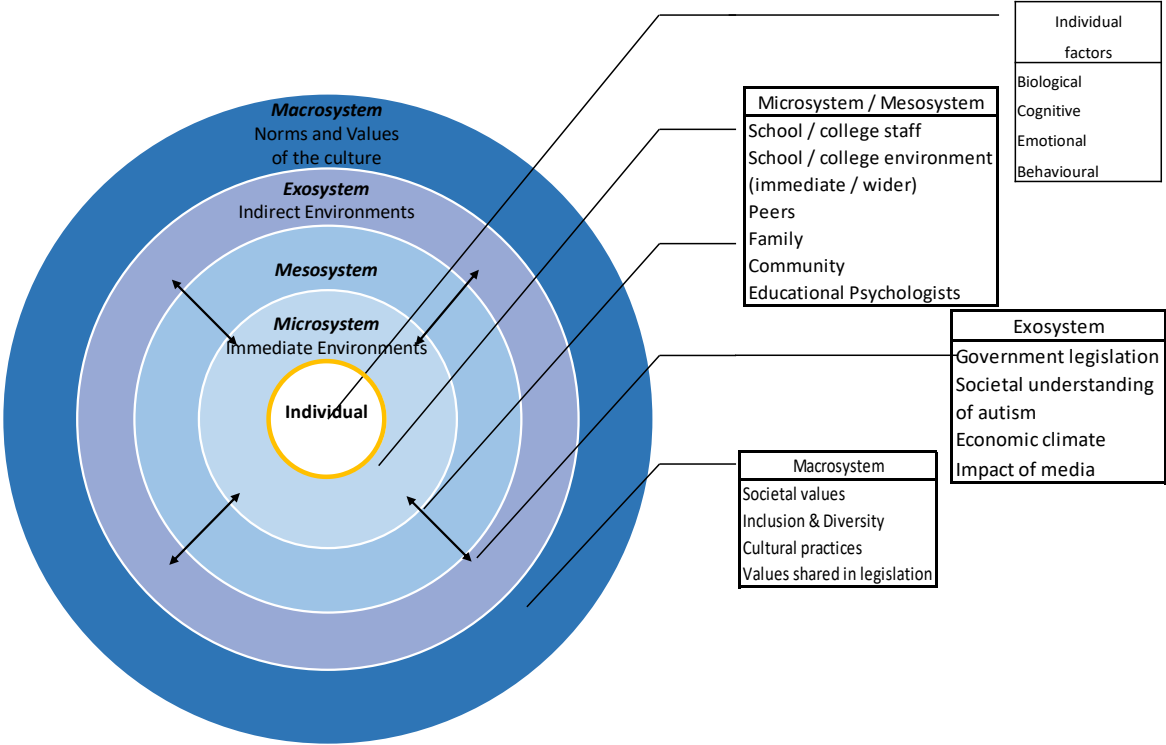
A holistic approach is recommended to support children and young people during transitional phases (O'Toole, Hayes and Mhathuna, 2014) and an ecological framework is considered suitable to support understanding, and in planning effective support for young people with autism during post-sixteen transition (Toor et al. 2016; Dente and Parkinson Coles, 2012).

5.11. An intervention framework: Bio-ecological systems theory

I believe that Bronfenbrenner and Ceci's bio-ecological systems theory (1994) is an effective one in illustrating the multiple influences that may impact on the experiences of young people with autism across their lives and also identifies where support can be appropriately targeted. I believe that the bidirectional influences are important in understanding an individual's development within the surrounding environmental context. The current study emphasises the multiple influences which impacted on the lives of the participants but also the individual differences between them (biological,

cognitive, emotional and behavioural). This meant that they responded in personal and unique ways to the systems around them.

Figure 4: Bio-ecological systems theory (1994)



I will initially outline some general guidelines for educational professionals who work directly with the young person. These have been developed from the findings in the current study and are also supported by other research and literature. The parts of the model which have the most relevance during this stage are: the individual's interaction with the **Microsystem** (Immediate environment) and the connections made within the **Mesosystem**. I have chosen to include recommendations from studies where the young person's voice is central. This includes: Breakey (2006); Beardon et al. (2009); Chown and Beavan (2012); Mitchell and Beresford (2014); DfE, 2015b; Toor et al. (2016); Bell et al. (2017) and Hatfield et al. (2018)

It is important to re-iterate, as advocated in much literature pertaining to this group and supported by the findings in the current study, that 'one size does not fit all' (Breakey, 2006) and that there are many differences between the needs of individuals identified under the umbrella term of 'Autism Spectrum Disorder'. The recommendations are therefore considered to be a 'starting point' when planning the most effective support

and some flexibility is required in considering the specific needs of individuals. It is also expected that needs will change over time as an individual matures (Beardon et al, 2009).

I have divided the recommendations according to the stage at which they take place, for ease of understanding and to provide a focus for supporting adults around young people during this time. These have been broadly based on other studies regarding this transitional period (Mitchell and Beresford, 2014). For each stage I have also provided further divisions in reflecting the different contexts of the intervention. These include: Person-centred processes; Specific or specialist support; Communication between partners; Formal transition processes.

Table 14: Interventions at microsystem and mesosystem levels

Area of focus	Key considerations
<i>Decision-making</i>	<i>Years 9, 10 and 11.</i>
<i>Person-centred processes</i>	<ul style="list-style-type: none"> • Supporting the involvement of the young person in decision-making throughout secondary education is important to support the development of skills required for more formal transition planning processes later. Sensitivity will be required in supporting individual differences and any anxieties related to social communication and interaction. • Young people need a good understanding of the purpose of the transition process so that they are motivated to be more involved. • It is important that strengths and interest- focused approaches are used in early planning. Unique and individual needs should be identified. Acknowledging the personal histories of the young people will support a more holistic understanding of their needs.

	<ul style="list-style-type: none"> • The young person should be encouraged to share their views using a medium in which they feel comfortable during early transition meetings. For example, using person-centred planning tools such as a 'one-page profile' may help the young person to identify their strengths and interests and provide an initial focus. • Supporting the young person to build confidence, through continued involvement in transition-planning and encouraging skills in self-determination should be a consistent focus in transition-planning. • Some young people may benefit from engaging with others with a similar diagnosis who are approaching the transition planning stage.
<i>Specific or specialist support</i>	<ul style="list-style-type: none"> • Opportunities to develop trusting relationships with key members of staff in the new provision should be established as soon as possible. • Support for developing social skills and problem-solving abilities should be established and ongoing throughout this period. • Careers support should be provided from a trained professional with knowledge of autism. Conversations should be related to career progression and longer-term aspirations as well as course or college choices.
<i>Communication between partners</i>	<ul style="list-style-type: none"> • A partnership approach should be adopted when working with parents/ carers where information can be shared to achieve a holistic understanding of the young person, for example, related to their past experiences,

	<p>individual preferences and personal strengths and resources.</p> <ul style="list-style-type: none"> • It is important that regular dedicated time is reserved for transition planning, preparation and liaison between partners. • Regular visits to the college premises should be established for the young person at an early stage as well as opportunities to develop relationships with key members of college staff. • Experiential learning activities are important for young people with autism so that they can practice their skills and develop new skills and abilities related to their interests. This will require close liaison between school and the further education provision.
<i>Formal transition processes</i>	<ul style="list-style-type: none"> • Transition-planning should begin in year 9, when choices regarding GCSE options are related to early career-thinking (DfE, 2014a). • Formal paperwork should include a clear plan with distinct steps which can be monitored and updated on a regular basis. • A clear transition plan should be prepared as early as possible. A 'transition-team' approach could be used with a key adult from secondary school to coordinate the process. A member of staff from the future provision should also be involved early in the process.
<i>Preparing for the move to college.</i>	Year 11
<i>Person-centred processes</i>	<ul style="list-style-type: none"> • Young people should have a clear understanding of the changes in the year 11 timetable over this period and the expectations on them.

	<ul style="list-style-type: none"> Identifying other young people who are in the same year group, who can provide a 'buddying role' may be helpful for some young people. Schools should to be flexible with the end of year arrangements for individual young people during this period and be aware of heightened anxieties around unfamiliar and sensory-demanding activities.
<i>Specific or specialist support</i>	<ul style="list-style-type: none"> Access to psychological, mentoring, counselling and coaching services should be available, as required. Specific programmes should be identified and established as required, for example, travel-training and practice for walking routes. Strategies to manage particular concerns should be discussed. Regular individual work with a trained member of staff may support some young person to identify the differences between the school and college environment and problem-solve any issues.
<i>Communication between partners</i>	<ul style="list-style-type: none"> Key staff should acknowledge concerns around the demands in year 11 and ensure that the support of teaching staff is available for the young person to plan and prepare for exams, if required. There should continue to be close liaison between school staff and key members of college staff. A key adult should continue to assume the co-ordinating role for transition processes, providing information in a range of formats.
<i>Formal transition processes.</i>	<ul style="list-style-type: none"> Summer programmes should be established where students can spend time during the summer familiarising themselves with the college environment and the different expectations related to this.

	<p>Opportunities to visit the college during a quiet or holiday period may help young people with particular anxieties, which may be enhanced in a busy and noisy atmosphere.</p> <ul style="list-style-type: none"> • Transition-planning documentation should be updated regularly to reflect the processes that are in place and any changes over this time. • At this stage, further education college staff should be a consistent presence in supporting individuals with any transition questions or concerns.
<i>Settling into college</i>	Year 12 - Terms one and two.
<i>Person-centred processes</i>	<ul style="list-style-type: none"> • Personal qualities of adults in supporting roles are important. Knowledge, experience and understanding of autism is essential as well as being able to respond to young people in an empathic and non-judgemental way. Predictable and reliable support is important. • It is necessary to provide information in a clear, unambiguous and accessible way. Using technology to share messages may be helpful to support individuals who may prefer this.
<i>Specific or specialist support</i>	<ul style="list-style-type: none"> • Buddying, befriending approaches or peer mentors may be helpful to support young people with wider aspects of college life. • Staff mentors may support the young person to become familiar with the organisational requirements of their learning programme and be available to address individual concerns. Written information should support verbal information.

	<ul style="list-style-type: none"> • Careers support should be available and ongoing throughout the year.
<i>Communication between partners</i>	<ul style="list-style-type: none"> • Further education colleges should follow the advice and guidelines outlined in the AET resources (2018). • College staff should be aware of the implicit social demands embedded in the curriculum, including assessment processes, and prepare students accordingly. • Autism understanding should be embedded within the college, with training for all staff and autism awareness events promoted within colleges to support the understanding of non-autistic students.
<i>Formal transition processes.</i>	<ul style="list-style-type: none"> • Continuing to liaise with parents / carers is important to ensure that the support needs of the individual are recognised, and strategies are put into place. • A collaborative approach between school and college should continue into the first terms of college to facilitate the sharing of good practice which focuses on the needs of the individual. • Transition plans should continue throughout this period with a focus on monitoring and reviewing the progress of the young person and any concerns that they might have. • The transition plan should more widely reflect the aims in the 'preparing for adulthood' documentation in promoting independence in the young person (Preparing for Adulthood, 2013).

I will now outline further implications which are relevant for other people who may have a role within the **Mesosystem**, in particular, Educational Psychologists. I will also consider

the influences of the outer layers of Bronfenbrenner's model on the individual, which includes the **Exosystem** (Indirect environment) and the **Macrosystem** (Social and Cultural values).

5.12. Implications for Educational Psychologists

There is a professional and moral obligation for Educational Psychologists (EPs) to support the development of sustainable and inclusive educational environments where the needs of all young people are accommodated (BPS, 2005). At the present time, there is evidence to suggest that not all educational establishments are fulfilling their obligation (Ambitious for Autism, 2011; APPGA, 2017) and this also applies to statutory duties, in giving full regard to the needs of those on the autism spectrum (Ofsted, 2016; AET, 2018a).

For all children and young people with a range of additional needs, times of transition can lead to particular challenges. Needs which are more specifically related to those on the autism spectrum during this period have been identified within this study. In the United Kingdom, the role of Educational Psychologists in post-16 transition is an area that is receiving more attention (Geiger, Freedman and Johnston, 2015) but in the review by Morris and Atkinson (2018) it was clear that much of the 'evidence' in support of the EP role, was found in unpublished theses. This suggests that it is a developing area and one where further research similar to the current study, will be useful.

The capacity for EPs to work at different levels is increasing, which includes: at a government policy level; an individual level working with pupils and with 'systems' around the young person, including parents and school staff (Fallon, Woods and Rooney, 2010; Ashton and Roberts, 2006). EPs clearly have a role in advocating for individual young people and supporting staff with their understanding of the needs of young people with autism within an educational environment. This includes fostering an appreciation of the individual differences of young people who share a diagnosis of ASD and applying a holistic approach to support greater understanding. For EPs involved in supporting individual young people, I would share the view of Begon and Billington (2019):

Ultimatelythe aim for EPs is to develop interventions that embody something of the complexity and nuance that characterises these individuals' own pursuit of self-advocacy and self-determination (p191).

There is also a clear role for EPs in supporting effective transition-planning processes within schools and further education colleges. Working closely with parents as well as educational establishments suggests that EPs can provide a link role between the different parties throughout the transition process. Improving the capacity of staff within educational environments is also important, which may include training key staff within both secondary and further education provisions, to fulfil over-arching, co-ordinating roles. This could ensure closer and more effective liaison between schools and colleges, resulting in a smoother transition process for the young person involved.

There may also be a part for EPs in commissioning new research and involving young people with autism spectrum conditions as co-researchers (Milton, 2014). Further exploration of a range of participatory approaches may support this (MacLeod, Lewis, Robertson, 2014). Research which explores the experience of transition from a longitudinal perspective will be much valued.

5.13. Implications for wider systems

The more general findings of the study and the literature that supports this, indicates that there are implications for the Exosystem and Macrosystem.

Recent reports (Ofsted, 2016; APPGA, 2017) reveal that there are areas of significant concern and evident shortcomings in the education provided for children and young people with autism. Legislative protection and the values which are fundamental to this, in supporting the rights of these children and young people are sometimes being disregarded (DfE, 2014a). There are legal implications in the practice of some schools in informally excluding young people with autism and for at least two of the participants in the current study, they had experienced this. The relationship between missed education and academic achievement has been established (DfE, 2016) but the wider psychological impact is less clearly acknowledged (Doward, 2017) I would argue that local authorities and government organisations have a duty to address these issues.

A lack of adequate understanding of autism spectrum conditions is still evident across professionals and in wider school and community settings and this is a significant concern. Person-centred approaches, although advocated, may not being used effectively (Scott, 2017). Appropriate training and understanding of autism are clearly an essential

requirement when supporting young people on the autism spectrum and promotion of autism awareness should be embedded within college practices. Positive progress has been made in that guidelines and strategies related to good professional practice in supporting young people in the post-sixteen period are now in existence (DfE, 2018b; AET, 2017; AET, 2018a), but at the present time, it is unclear how extensively they have been implemented.

The role of local authorities in commissioning appropriate services to meet the needs of young people with autism during this transition stage is a statutory duty in the context of 'preparing young people for adulthood' (DfE, 2015a). There appears to be gaps at local authority level (APPGA, 2017), and this will have an impact on the effective commissioning of services to meet the wide range of needs of children and young people.

Within the study findings, there is a 'feeling of difference' observed by the participants and there are wider societal issues around the practice of assigning labels to delineate need and permit access to resources. Values related to inclusion and diversity and how these are shared are also issues apparent in this debate (Norwich 2006). This is a debate that will continue but with the persistent rise in the numbers of children and young people with an autism diagnosis, this indicates that there is an urgency in addressing these issues.

The aim of the current study has also been to challenge some of the stereotypes that exist regarding young people on the autism spectrum and I believe that this has, in part, been achieved. In acknowledging the sensitive handling that would be required to support others in understanding the autism spectrum, Beardson et al. (2009) propose:

...valuing rather than problematising diversity is some sort of starting point. Consigning words like 'normalisation' to the history book would be timely...valuing diversity necessarily involves a degree of sensitivity from individuals and a cultural shift from the top away from tolerating, to facilitating, towards valuing' (p42)

5.14. Implications for research

In the wider context of supporting young people over the extended period of transition, from year 9 onwards and the importance of person-centred practices (DfE, 2015a), there are many research implications that have emerged from this study.

An area of particular concern which has emerged from the current research is the lack of involvement of participants in specific transition processes, such as planning meetings. Research findings suggest that young people with autism are the least likely to attend or contribute to meetings, when compared to individuals with other additional needs (Griffen et al, 2014). This may demonstrate, at the present time, that their unique needs are not being catered for within the transition process. It is imperative to explore the processes involved in this and consider the most effective ways to empower young people to contribute.

A clearer picture is required regarding the processes involved in the development of learning programmes within further education. Restrictions within specific programmes will have an implication for individual career progression in a competitive employment environment and this is an area of hugely significant concern. Research may also help us to answer questions related to the demands of specific courses and how these relate to areas of difficulty experienced by young people on the autism spectrum.

In considering research with children and young people, it has been recognised that parents can sometimes act as gatekeepers (Beresford et al, 2004) and I encountered this in my study. With respect for parental opinion, it should be acknowledged that, when given an opportunity, children and young people with autism, may express different views to their parents (Camarena and Sargiani, 2009). I have some sympathy with the view that young people should be offered the choice to be involved in research which is relevant to them, and that it may be disempowering for young people on the autism spectrum to have this choice removed (Milton, Mills and Pellicano, 2014).

Within my study there was little consideration of the family or ethnic background of the participants, and it is possible that these characteristics could have had an effect on their experiences and potentially their attitude towards transition and/ or further education. There is evidence that socio-economic factors may have an impact on attitudes towards

further education (OECD, 2011). Furlong and Cartmel (2006) suggest that inequalities associated with class still need to be addressed, but for Rydzewska (2012) inequalities for young people with ASD should be considered on a more ontological, personal level. I suspect that all of these views have some validity and may warrant further research.

5.15. Summary of the chapter

This chapter has considered the findings of the current research study with regard to the literature in the area and discussed implications for future practice and potential research.

The findings and the current literature indicate that post-sixteen transition takes place at a developmentally sensitive period, within adolescence, and that the features of this developmental stage may enhance difficulties that young people with autism may experience. For the participants in the current study, this time was characterised by leaving behind a period of relative stability in secondary education and moving into a time of uncertainty related to transition and the post-sixteen education environment.

In relating the findings to Erikson's Psychosocial theory (1968), I believe that it is important to note that identity exploration is a feature of adolescence for all young people, and that some of the expectations and aspirations of the participants can be seen in the context of 'typical' adolescent experience (Siegel, 2013). In the context of this theory however, it is possible that these young people may be at increased risk of 'identity diffusion' as they mature within a society which may, at the present time, potentially lacks an understanding of their needs and an ability to fully accommodate them.

Links to the literature concerning aspects of this topic area have included: the challenges of educational transition taking place during adolescence (Wing, 1996); the significance of supportive adult relationships (Bell et al, 2017) and difficult peer relationships (Jackson, 2002); the important role of parents and how this relates to the developing independence of young people (Mitchell and Beresford, 2014); the connection between transition and adult outcomes (NAS, 2016) and the exploration of identity during this time (Humphrey and Lewis, 2008; Erikson, 1968). The findings have also supported previous findings which relate to limitations within transition processes, which include those at the planning and

preparation stage (Mynatt et al. 2014), as well as those experienced by the participants immediately prior to the physical transition process and in the early days of college (Beardon et al, 2009). Research which considers the lack of accommodation in further education provision for those on the autism spectrum and recognises a training need for adults who work in this environment has also been supported (Breakey, 2006; APGGA, 2017).

Chapter 6

Conclusion

6.1. Chapter overview

This chapter aims to:

- Assess the quality of the study through using the established framework by Lucy Yardley (2000).
- Contribute personal thoughts on reflexivity within research.
- Include some final reflections on the research journey overall.

My experience as a researcher in the past was minimal and although I have previously completed a project at undergraduate level, I had very little experience of using qualitative methods. My chosen methodology of Interpretative Phenomenological Analysis (IPA) was also unfamiliar to me and I believe that this research has contributed to my knowledge and development as a qualitative researcher. It was essential as the researcher and respectful to the research participants that this study met high quality standards and I have used Yardley's framework (2000) to ensure this. This framework has been advocated as one which is particularly suited to assessing IPA studies (Smith et al, 2009; Hefferson and Gil-Rodriguez, 2011).

6.2. Assessing qualitative research

Yardley (2000) suggests 'open-ended and flexible principles' to guide quality, which are:

- Sensitivity to context
- Commitment and rigour
- Transparency and coherence
- Impact and importance.

6.2.1. *Sensitivity to Context*

In Yardley's view, 'sensitivity to context' should include sensitivity to the literature concerning the topic area; the views of the participants and the socio-cultural context that surrounds them. Yardley (2000) also believes that researchers should also actively engage with knowledge and views that do not necessarily represent their own and there should also be an awareness of ethical issues which affect the research relationship. This

includes an attempt by the researcher to reduce the power imbalance, as well as an acknowledgment of the importance of reflexivity.

In attempting to achieve 'Sensitivity to Context' the following methods were employed: A systematic literature review which covered the period of post-sixteen transition to ensure that I had identified relevant studies and reports that were related to this topic. The Discussion chapter then related the findings to the literature explored in the Literature Review, which would further set the study in context.

There are many ethical issues in research with young people and particularly those deemed more vulnerable, and at all times within the research process this has been a prime consideration, as explained in the Methodology section. I also attempted to manage the inherent imbalance in the research relationship by, for example, acknowledging that certain aspects of the research environment might be discomforting to the participants and adopting measures to address this.

Uncertainty can lead to anxiety, which can be a debilitating feature for some young people on the autism spectrum and I took steps to attempt to reduce this. Examples of this were: producing structured information prior to and throughout the research process; providing clarity around the structure and timings of meetings; introducing a 'Stop' card that the participant could use at any point in the interview. The use of a semi-structured interview format also meant that the participants were able to 'lead' the interview, to some degree, in a direction of their choosing. Although a 'verbal culture' may put young people with autism at a disadvantage (Breakey, 2006), as far as I was able, I attempted to ensure that the participants were at ease throughout the interaction and was sensitive to signs that may indicate otherwise.

6.2.2. *Commitment and rigour*

Commitment and rigour is the second aspect proposed by Yardley (2000) to ensure sufficient quality in qualitative research. This refers to 'the usual expectations for thoroughness in data collection, analysis and reporting in any kind of research' (p221). This commitment was demonstrated within the current research study by the processes employed in the study, from the point of preparing for data collection through to the analysis and report-writing. I adhered closely to the processes outlined by Smith et al.

(2009) and the level of analysis which is required in an IPA study demanded a significant commitment, in terms of time, as well as emotional and intellectual involvement. I would also argue that this commitment was further enhanced by my personal interest and past professional background, which led to an increased interest in the value of research in this area. The nature of IPA in moving from the 'part' to the 'whole' and the cyclical aspect of the process (Smith et al, 2009), demanded a high level of immersion and reflection of the data over the full course of the research. In my view, this resulted in a very thorough and rigorous analysis and reporting of the data.

6.2.3. *Transparency and Coherence*

'Transparency and coherence' is apparent at the level of presentation of the research and in providing a convincing account of a reality co-created throughout the research process. (Yardley, 2000, p222). For Yardley, this also relates to the 'fit' between the research question and the approach taken. The aim of the current research was to explore the 'unique' perspective of the participants throughout the post-sixteen period and in respect of this, the words of the individuals are clearly included in the research. Within the Findings and Discussion chapters, I have outlined the interpretations that were formed from the words in the participants' stories. This helps to provide transparency and coherence within the narrative of the research. A clear explanation of the process, as well as inclusion of sections of coded transcripts adds further to the research story.

6.2.4. *Impact and importance*

In the final criteria for quality research, Yardley describes the 'impact and importance' of the research. This can be a subjective judgement but for Yardley (2000) it can imply a 'theoretical and practical' sense and for some qualitative researchers', research which results in a 'sociocultural impact'.

I would argue that the current research has offered a 'new and challenging' perspective in that the accounts of the individual participants' offer different views on a similar experience. The voices of young people with autism has been an area neglected in research and this must give additional importance to their stories. The longer-term impact of the study is unknown at the present time, but if we are to 'make a difference' to the lives of children and young people, we must appreciate the value in hearing their

personal stories. As noted at other points in the current study, there is a danger that the diagnostic label of ASD, fails to appreciate the degree of individual differences amongst the people who share it and the current research adds a little more to this debate.

6.3. Reflexivity

It has been increasingly recognised that reflexivity is an essential strategy in the process of knowledge generation within qualitative research (Berger, 2015, p219). There are differences of opinions in the interpretation and construction of reflexivity (Primeau, 2003), although there is some agreement as to the meaning, which Berger (2015) describes as:

The process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome (p220).

I would concur that it is important to acknowledge the position of the researcher in relation to their research and would agree with Willig (2013) that biases should not be 'removed' from the research but accepted as 'conditions which frame, and indeed make possible, the research' which will 'inevitably shape the research and its findings' (p52).

In my experience, the influence of the participants meant that the research 'knowledge' produced was co-constructed with them as part of a dynamic process. This supports the social constructionist perspective in that data generated is a joint product of the researcher-participant interaction (Huberman and Miles, 2002).

There is a view that researchers should 'bracket' their pre-conceptions before approaching research (Smith, 2003, p12). I would argue that this may be an unrealistic aim and that extensive personal and professional experience of individuals on the autism spectrum, meant that 'bracketing' all pre-conceptions was a challenge. I am aware that my emotional responses have developed over time and in response to a range of experiences and that this will have had an impact on the way that I approached the research, and to some degree, interacted with the participants.

6.4. Reflections on the research process

I will borrow the metaphor of a 'journey', as used by one of the participants in the study to describe my research experience, because I feel that it is appropriate in defining this process. I noted a possible description of 'research' in a textbook, which suggested that it:

... involves opening up to new and possibly unsettling experiences (Willig, 2013, p3).

I believe that this effectively describes my research journey and I was both unsettled and exhilarated by the process. The unreserved accounts of the young people in re-calling some very difficult experiences indicated a level of self-reflection that I wasn't anticipating. The IPA process itself and the level of immersion required in analysing the participants' accounts, required an emotional engagement with the participants' experiences that has, on occasions, felt overwhelming. The importance of honouring their stories has compelled me to maintain the energy and enthusiasm required to complete a challenging journey. I am very grateful to each of the participants for the time that they spent with me, in sharing their stories.

REFERENCES

- Acker, L., Knight, M and Knott, F (2018) "Are they just gonna reject me?" Male adolescents with autism making sense of anxiety: An Interpretative Phenomenological Analysis'. *Research in Autism Spectrum Disorders*, Vol 56, pp. 9-20.
- Adreon, D and Durocher, J, S (2007) 'Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders' *Intervention in School and Clinic*. Vol. 42, No. 5, pp. 271-279.
- All Party Parliamentary Group for Autism (APPGA, 2017). *Autism and education in England*. London: The National Autistic Society.
- Ambitious for Autism (2011) *Finished at School* (Online).
- Accessed at:
https://www.ambitiousaboutautism.org.uk/sites/default/files/Finished_at_School_guide.
(10th January 2018).
- American Psychiatric Association (APA) 2013. *Diagnostic and Statistical Manual of Mental Disorders*. 5th edition. Arlington, VA: American Psychiatric Publishing.
- Anderson, K, A., Sosnowy, C., Kuo, A, A and Shattuck, P, T (2018) 'Transition of Individuals with Autism to Adulthood: A Review of Qualitative Studies' *Paediatrics*, Vol. 141, Issue supplement 4, pp. 1-13.
- Arnett, J, J (2000) 'Emerging adulthood. A theory of development from the late teens through the twenties' *American Psychologist*, Vol. 55, No. 5, pp. 469-480.
- Ashton, R and Roberts, E (2006) 'What is Valuable and Unique about the Educational Psychologist'. *Educational Psychology in Practice*, Vol. 22, No. 2, pp. 111-123.
- Autism Education Trust (2009) *Educational provision for children and young people on the autism spectrum living in England: a review of current practice, issues and challenges* (online). Accessed at: www.autismeducationtrust.org.uk. (29th December 2018).
- Autism Education Trust (2017) 'A guide to the use of the AET post 16 programme by local authorities, support services and college' (Online).

Accessed at: <http://www.aettraininghubs.org.uk/wp-content/uploads/2017/03/AET-P16-guidance-20.03.2017.pdf>. (10th June 2018).

Autism Education Trust (2018a) *Post-16 programme: Competency framework* (Online).

Accessed at: <http://www.aettraininghubs.org.uk/post-16/> (8th January, 2019).

Autism Education Trust (2018b) *Post-16 programme: Autism standards* (Online)

Accessed at: <http://www.aettraininghubs.org.uk/post-16/> (8th January, 2019)

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D and Charman, T (2006) 'Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)'. *The Lancet*, Vol. 368, No. 9531, pp. 210-215.

Bandura, A. (1977). 'Self-efficacy: Toward a unifying theory of behavioral change'. *Advances in Behaviour Research and Therapy*, Vol. 1, No.4, pp.139-161.

Baric, V, B., Hemmingson, H., Hellberg, K and Kjellberg A (2017) 'The Occupational Transition Process to Upper Secondary School, Further Education and/or Work in Sweden: As Described by Young Adults with Asperger Syndrome and Attention Deficit Hyperactivity Disorder'. *Journal of Autism and other Developmental Disorders*, Vol. 47, pp. 667-679.

Barnhill, G (2007) 'Outcomes in adults with Asperger Syndrome'. *Focus on Autism and other Developmental Disorders*. Vol. 22, No. 2, pp. 116-126.

Baron-Cohen, S (2002) 'Is Asperger syndrome necessarily referred to as a disability?' *Focus on Autism and Other Developmental Disabilities*. Vol. 17, pp. 186-191.

Baron-Cohen, S (2008) *Autism and Asperger syndrome*. Oxford: Oxford University Press.

Barrow, L, C (2013) *Exploring the Post 16 transition experiences of pupils with Autistic Spectrum Disorders*. (Unpublished Doctoral Thesis). Newcastle University.

Accessed at: <https://ethos.bl.uk/> (10th June 2017)

Baumeister, R, F (1990) Identity crisis. In R. Gunn (Eds.) *The Encyclopedia of Adolescence* (Vol. 1, pp. 518-521) New York: Garland.

Beardon, L (2017) *Autism and Asperger Syndrome in Adults*. London: Sheldon Press.

Beardon, L., Martin, N and Woolsey, I (2009) 'What do students with Asperger syndrome and high-functioning autism want at college and university?'. *Good Autism Practice*, Vol. 10, No. 2, pp.35-43.

Beardon, L and Worton D (2017) *Bittersweet on the autism spectrum*. London: Jessica Kingsley Publishers.

Begon, R and Billington, T (2019) 'Between category and experience: constructing autism, constructing critical practice'. *Educational Psychology in Practice*, Vol. 35, No. 2, pp. 184-196.

Bell, S., Devecchi, C, McGuckin and Shevlin, M (2017) 'Making the transition to post-secondary education: opportunities and challenges experienced by students with ASD in the Republic of Ireland'. *European Journal of Special Needs Education*, Vol. 32, No. 1, pp. 54-70.

Beresford, B., Tozer, R., Rabiee, P and Sloper, P (2004) 'Developing an approach to involving children with autistic spectrum disorders in a social care research project'. *British Journal of Learning Disabilities*. Vol. 32, pp180-185.

Beresford, B, M., Tozer, R., Rabiee, P and Sloper (2007) 'Desired Outcomes for Children and Adolescents with Autistic Spectrum Disorders' *Children and Society*, Vol. 21, pp. 4-16.

Berger, R (2015) 'Now I see it, now I don't: researcher's position and reflexivity in qualitative research' *Qualitative Research*, Vol. 15, No. 2, pp 219-234.

Berk, L (1997) *Child Development: Fourth Edition*. London: Allyn and Bacon.

Bogdashina, O (2003) *Sensory Perceptual Issues in Autism and Asperger Syndrome*. London: Jessica Kingsley Publishers.

Braun and Clarke (2013) *Successful Qualitative Research: A Practical Guide for Beginners*. London: Sage.

Breakey, C (2006) *The autism spectrum and further education: A guide to good practice*. London: Jessica Kingsley Publishers.

British Psychological Society (2005) 'Inclusive Education-part of a changing society'.

(Online) Accessed at: www.bps.org.uk (10th October 2016).

British Psychological Society (2018) *Code of Ethics and Conduct*. Leicester: BPS.

Brocki, J, M and Weardon, A, J (2006) 'A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology'. *Psychology and health*, Vol. 21, No. 1, pp. 87-108.

Bronfenbrenner, U and Ceci, S, J (1994) 'Nature-nurture reconceptualized in developmental perspective: A bioecological model'. *Psychological Review*, Vol. 101, No. 4, pp. 568-586

Browning, J., Osborne, L, A and Reed, P (2009) 'A qualitative comparison of perceived stress and coping in adolescents with and without autistic spectrum disorders as they approach leaving school'. *British Journal of Special Education*. Vol. 36, No. 1, pp.36-43.

Brugha, T., Cooper SA, McManus S, Purdon S, Smith J, Scott FJ, Spiers N, Tyrer F (2012). The NHS Information Centre, Community and Mental Health Team, *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*. Leeds: NHS Information Centre for Health and Social Care

Cai, R, Y and Richdale, A, L (2016) 'Educational Experiences and Needs of Higher Education Students with Autism Spectrum Disorder' *Journal of Autism and Developmental Disorders*. Vol. 46, pp. 31-41.

Camarena, P, M and Sarigiani, P, A (2009) 'Postsecondary Educational Aspirations of High-Functioning Adolescents with Autism Spectrum Disorders and Their Parents'. *Focus on Autism and Other Developmental Disabilities*. Vol. 24, No. 2, pp. 115-128.

Care Act (2014) London: HMSO. (Online). Accessed at: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>. (10th January 2018)

Carrington, S and Graham, L (2001) 'Perceptions of school by two teenage boys with Asperger syndrome and their mothers: a qualitative study'. *Autism*, Vol. 5, No. 1, pp. 37-48.

Carrington, S., Templeton, E and Papinczak (2003) 'Adolescents with Asperger Syndrome and Perceptions of Friendship' *Focus on Autism and Other Developmental Disabilities*. Vol. 18, No. 4, pp. 211-218.

CentreForum Commission on Children and young People's Mental Health (2016) *State of the Nation*. London: CentreForum.

Chamberlain, K (2011) 'Troubling methodology'. *Health Psychology Review*, Vol. 5, No. 1, pp. 48-54.

Chambres, P., Auxiette, C., Vansingle, C and Gil, S (2008) 'Adult Attitudes Toward Behaviors of a Six-year-old Boy with Autism'. *Journal of Autism and other Developmental Disorders*. Vol. 38, pp. 1320-1327.

Charmaz, C. (2006) *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage

Chavez, J (2017) *Researcher position and reflexivity essay*. University of Bristol

Chown, N and Beavan, N (2012) 'Intellectually capable but socially excluded? A review of the literature and research on students with autism in further education' *Journal of Further and Higher Education*. Vol. 36, No. 4, pp. 477-493.

Council for Disabled Children – (online)

Accessed at (www.councilfordisabledchildren.org.uk) on 15/12/2018.

Connor, M (2000) 'Asperger Syndrome (Autistic Spectrum Disorder) and the Self-Reports of Comprehensive School Students'. *Educational Psychology in Practice*. Vol. 16, No. 3, pp. 285-296.

Council for Disabled Children (2018) 'SEN data bulletin: What can we learn from national data on children and young people with special educational needs (SEN)?' (Online)

Accessed at:

<https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/SEN%20data%20bulletin.pdf> (20th November, 2018).

Dann, R (2011) 'Secondary transition experiences for pupils with Autistic Spectrum Conditions'. *Educational Psychology in Practice*. Vol. 27, No. 3, pp. 293-312.

Davis J, M and Watson, N (2001) 'Where are the children's experiences? Analysing the social and cultural exclusion in special and mainstream schools'. *Disability and Society*, Vol. 16, No. 5, pp. 671-687.

Dente, C, L and Parkinson Coles, K (2012) 'Ecological Approaches to Transition Planning for Students with Autism and Asperger's Syndrome'. *Children and Schools*, Vol. 34, No. 1, pp. 27-35.

Department for Education (2002). *Autistic spectrum disorders: Good practice guidance*. 'Transitions and moving to post-school provision'.

Department for Education (2008) *Education and Skills Act*. London: HMSO.

Department for Education (2009) *Autism Act*. London: HMSO.

Department for Education (2014a) *The Children and Families Act*. London: HMSO.

Department for Education (2014b) Statistical First Release - Special Educational Needs in England: January 2014 (online)

Accessed at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/362704/SFR26-2014_SEN_06102014.pdf (22nd November, 2018).

Department of Education (2014c) *Think Autism*. (Online).

Accessed at: <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy> (2nd March 2018).

Department for Education (2015a) *Special Education Needs and Disabilities (SEND) Code of Practice: 0-25 years*. London: HMSO.

Department for Education (2015b) *Supporting young people with autism to move from school to college: Learning from Ambitious About Autism's Finished at School Programme*. London: HMSO.

Department for Education (2016) *The link between absence and attainment at KS2 and KS4: 2013/14*. London: HMSO.

Department for Education (2018a) *Destinations of key stage 4 and key stage 5 students, England, 2016/17* (Online).

Accessed at: <https://assets.publishing.service.gov.uk/> (January 3rd, 2019).

Department for Education (2018b) *Departmental advice for education providers on the planning and delivery of 16 to 19 study programmes*. London: HMSO.

Department for Education and Skills (2002) *Autistic spectrum disorders: Good practice guidance – Pointers to good practice* (online)

Accessed at: <http://www.autismtoolbox.co.uk/resources/reading-list/autism-spectrum-disorders-good-practice-guidance-2002/> (15th June, 2018).

Department for Universities, Innovation and Skills (2008) *DIUS's Departmental Report*. (Online)

Accessed at:
<https://publications.parliament.uk/pa/cm200809/cmselect/cmdius/51/51i.pdf> (January 15th 2018).

Department of Health (2010) 'Implementing "Fulfilling and rewarding lives": Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy'. (Online).

Accessed at: <http://www.dh.gov.uk/publications> (10th January 2018).

Department of Health (2015) 'Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy' (Online)

Accessed at: <http://www.dh.gov.uk/publications> (10th January 2018).

Dewinter, J., Parys, H, V., Vermeiren, R and van Nieuwenhuizan, C (2017) 'Adolescent boys with autism spectrum disorder and their experience of sexuality: An interpretative phenomenological analysis' *Autism*, Vol. 21, no. 1, pp. 75-82.

Dillon, G, V and Underwood, J, D, M (2012) 'Parental Perspectives of Students with Autism Spectrum Disorders Transitioning from Primary to Secondary School in the United Kingdom' *Focus on Autism and Other Developmental Disabilities*, Vol. 27, No. 2, pp. 111-121.

Dillon, G, V., Underwood, J, D, M, Freemantle, L, J (2014) 'Autism and the U.K. Secondary School Experience' *Focus on Autism and Other Developmental Disabilities*, Vol. 31, Vol. 3, pp. 221-230.

Doward, J (2017) 'School exclusion 'linked to long-term mental health problems' – study. *The Guardian*, Saturday 19th August 2017. (Online). Accessed at: <https://www.theguardian.com/education/2017/aug/19/school-exclusion-linked-to-long-term-mental-health-problems>. (9th October 2017).

Eaves, L, C and Ho, H, H (2008) 'Young Adult Outcome of Autism Spectrum Disorders' *Journal of Autism and Developmental Disorders*, Vol. 38, pp. 739-747.

Eccles, J, S and Roeser, R, W (2011) 'Schools as Developmental Contexts During Adolescence', *Journal of Research on Adolescence*, Vol. 21, No. 1, pp. 225-241.

Erikson, E (1968) *Identity – Youth and Crisis*. London: Faber and Faber Limited.

Equality Act (2010) London: HMSO. (Online). Accessed at: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>. (10th January 2018)

Fade, S. (2004) 'Using interpretative phenomenological analysis for public health nutrition and dietetic research: A practical guide', *Proceedings of the Nutrition Society*, Vol. 63, pp. 647–653.

Fallon, K., Woods, K and Rooney, S (2010) 'A discussion of the developing role of educational psychologists within Children's Services'. *Educational Psychology in Practice*, Vol. 26, No. 1, pp.1-23.

Festinger, L (1954) *A Theory of Social Comparison Processes*. Indianapolis: Bobbs-Merrill.

Foundation for People with Learning Disabilities (2017) 'We can dream'. (Online) Accessed at:

<https://www.mentalhealth.org.uk/learning-disabilities/our-work/getting-the-right-support/we-can-dream>. (5th August 2017).

Freud, S (1905) *Three essays on the theory of sexuality: The 1905 edition*. Verso Books.

Furlong, A and Cartmel, F (2006) *Young People and Social Change: New Perspectives*. Maidenhead: Open University Press.

Garth, B and Aroni, R (2003) ‘“I value what you have to say”. Seeking the perspective of children with a disability, not just their parents’. *Disability and Society*, Vol. 18, No. 5, pp. 561-576.

Geiger, S., Freedman, R and Johnston, L (2015) ‘Using action research to develop quality 16+ further education provision for young people with complex needs’. *Educational and Child Psychology*, Vol. 32, No. 1, pp. 80-92.

Grandin, T (2006) *Thinking in Pictures*. New York City: Vintage.

Grandin, T and Panek, R (2014) *The Autistic Brain*. London: Rider.

Gray, C (2010) *The New Social Story Book*. Florida: Future Horizons Inc.

Greene, S and Hill, M (2005) ‘Researching children’s experience: Methods and methodological issues. In S Greene and D Hogan (Eds.) *Researching children’s experience*. London: Sage.

Griffen, M, M., Taylor, J, L., Urbano, R, C and Hodapp (2014) ‘Involvement in Transition Planning Meetings Among High School Students with Autism Spectrum Disorders’ *The Journal of Special Education*, Vol. 47, No. 4, pp. 256-264.

Hagner, D., May, J., Kurtz, A and Cloutier, H (2014) ‘Person-Centred Planning for Transition-Aged Youth with Autism Spectrum Disorders’. *Journal of Rehabilitation*, Vol. 80, No. 1, pp.4-10.

Harrington, C., Foster, M., Rodger, S and Ashburner, J (2013) ‘Engaging young people with Autism Spectrum Disorder in research interviews’. *British Journal of Learning Disabilities*. Vol. 42, No. 2, pp153-161.

Hatfield, M., Falkmer, M., Falkmer, T and Ciccarelli, M (2017) “‘Leaps of faith’: parents and professionals’ viewpoints on preparing adolescents on the autism spectrum for leaving school’. *Journal of Research in Special Educational Needs*. Vol. 17, No. 3, pp. 187-197.

Hatfield, M., Ciccarelli, M., Falkmer, T and Falkmer, M (2018) ‘Factors related to successful transition planning for adolescents on the autism spectrum’, *Journal of Research in Special Educational Needs*, Vol. 18, No.1, pp. 3-14.

Hebron, J and Humphrey, N (2014) ‘Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: a comparative study’. *Journal of Research in Special Educational Needs*, Vol. 14, No. 1, pp. 22-32.

Hefferon, K & Gil-Rodriguez, E. (2011) ‘Interpretative phenomenological analysis’. *The Psychologist*, Vol. 24, No. 10, pp. 756-759.

Held, M, F., Thoma, C, A and Thomas, K (2004) “‘The John Jones Show’’: How One Teacher Facilitated Self-Determined Transition Planning for a Young Man with Autism’. *Focus on Autism and other Developmental Disabilities*, Vol. 19, No. 3, pp. 177-188.

Henderson, S., Holland, J., McGrellis, S., Sharpe, S and Thomson, R (2007) *Inventing adulthoods: a biographical approach to youth transitions*. London: Sage Publications.

Hendricks, D and Wehman, P (2009) ‘Transition from school to adulthood for youth with autism spectrum disorders: review and recommendations’. *Focus on Autism and Other Developmental Disabilities*, Vol. 24, No. 2, pp. 77-88.

Hill, L. (2014) "Some of it I haven't told anybody else': Using photo elicitation to explore the experiences of secondary school education from the perspective of young people with a diagnosis of Autistic Spectrum Disorder', *Educational & Child Psychology*, Vol. 31, No. 1, pp. 79-89.

Howlin, P. (2005). Outcomes in Autism Spectrum Disorders. In F.R. Volkmar, R. Paul, A. Klin & D.J. Cohen, *Handbook of autism and pervasive developmental disorders*, (Vol. 2, Assessment, Interventions and Policy, 3rd ed.)

- Howlin, P., Goode, S., Hutton, J and Rutter, M (2004) 'Adult outcome for children with autism'. *Journal of Child Psychology and Psychiatry*, Vol. 45, No. 2, pp212-229.
- Howlin, P and Moss, P (2012) 'Adults with Autism Spectrum Disorders'. *The Canadian Journal of Psychiatry*. Vol. 57, No. 5, pp. 275-283.
- Huberman, A, M and Miles, M, B (2002) *The Qualitative Researcher's Companion*. Thousand Oaks, CA: Sage.
- Humphrey, N and Lewis, S (2008) "Make me normal": The views and experiences of pupils on the autistic spectrum in mainstream secondary schools'. *Autism*. Vol. 12, No. 1, pp. 23-46.
- Huws, J, C and Jones, R, SP (2010) "'They just seem to live their lives in their own little world": lay perceptions of autism'. *Disability and Society*, Vol. 25, No. 3, pp. 331-344.
- Huws, J, C and Jones, R, SP (2015) "'I'm really glad this is developmental": Autism and social comparisons – an interpretative phenomenological analysis'. *Autism*, Vol. 19, No. 1, pp. 84-90.
- Individuals with Disabilities Education Act (2004) United States Congress.
- Jackson, L (2002) *Freaks, Geeks and Asperger Syndrome*. London: Jessica Kingsley Publishers.
- Jalali, S. and Wohlin, C. (2012) 'Systematic literature studies: Database searches vs. backward snowballing', *Empirical Software Engineering and Measurement*, Sweden.
- Jones, G (2015) 'Autism: enhancing whole school practice and the skills of the workforce'. *Journal of Special Educational Needs*. Vol. 15, pp.139-163.
- Jones, G., English, A., Guldberg, K., Jordan, R., Richardson, P and Waltz M (2009) *Educational provision for children and young people on the autism spectrum living in England: a review of current practice, issues and challenges. Summary Report - For parents and carers of children and young people on the autism spectrum*. London: Autism Education Trust.
- Kelly, B. (2005) "'Chocolate...makes you autism": impairment, disability and childhood identities'. *Disability and Society*, Vol. 20, No. 3, pp. 261-275.

Kim, J, A., Szatmari, P., Bryson, S, E., Streiner, D, L and Wilson, F, J (2000) 'The prevalence of anxiety and mood problems among children with autism and Asperger syndrome'. *Autism*, Vol. 4, No. 2, pp. 117-132.

Kvale, S. (2007). *Doing interviews*. London: Sage

Larkin, M., Watts, S and Clifton, E (2006) 'Giving voice and making sense in interpretative phenomenological analysis' *Qualitative Research in Psychology*. Vol.3, No. 2, pp. 102-120.

Levy, A and Perry, A (2011) 'Outcomes in adolescents and adults with autism: A review of the literature'. *Research in Autism Spectrum Disorders*. Vol. 5, pp.1271-1282.

Lewis, A. (2009) 'Methodological issues in exploring the ideas of children with autism concerning self and spirituality'. *Journal of Religion Disability and Health*, Vol. 13, pp. 64-76.

McKenzie, J, A (2013) 'Models of intellectual disability: towards a perspective of (poss)ability'. *Journal of Intellectual Disability*, Vol. 57, No. 4, pp. 370-379.

MacKenzie, H. (2008) *Reaching and Teaching the Child with Autism Spectrum Disorder: Using Learning Preferences and Strengths*. London: Jessica Kingsley Publishers.

MacLeod, A and Johnston, P (2007) 'Standing out and fitting in: a report on a support group for individuals with Asperger syndrome using a personal account'. *British Journal of Special Education*, Vol. 34, No 2, pp. 83-88.

MacLeod, A, G., Lewis, A and Robertson, C (2014) "'Charlie: please respond!'" Using a participatory methodology with individuals on the autism spectrum'. *International Journal of Research and Method in Education*. Vol. 37, No. 4, pp. 407-420.

Manzoni (2016) 'Conceptualizing and measuring youth independence: A multidimensional approach using latent class analysis', *Acta Sociologica*, Vol. 59, No. 4, pp. 362-377

Milton, D (2014) 'Autistic expertise: A critical reflection on the production of knowledge in autism studies'. *Autism*, Vol. 18, No. 7, pp. 794-802.

Milton, D., Mills, R and Pellicano, E (2014) 'Ethics and Autism: Where is the Autistic Voice? Commentary on Post et al.' *Journal of Autism and other Developmental Disorders*. Vol. 44, pp. 2650-2651.

Mitchell, W and Beresford, B (2014) 'Young people with high-functioning autism and Asperger's syndrome planning for and anticipating the move to college: what supports a positive transition?' *British Journal of Special Education*. Vol. 41, No. 2, pp. 151-171.

Moher, Liberati, Tetzlaff & Altman, (2009) 'Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLOS medicine*, Vol. 6, No. 7.

Accessed at: <https://doi.org/10.1371/journal.pmed>. (2nd August 2016)

Molloy, H and Vasil, L (2002) 'The Social Construction of Asperger Syndrome: The pathologizing of difference?' *Disability and Society*, Vol. 17, No. 6, pp. 659-669.

Morris, R and Atkinson, C (2018) 'The role of educational psychologists in supporting post-16 transition: findings from the literature'. *Educational Psychology in Practice*. Vol. 34, No. 2, pp. 131-149.

Muller, E., Schuler, A and Yates, G, B (2008) 'Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities' *Autism*, Vol. 12, No. 2, pp. 173-190.

Mynatt, B, S., Gibbons, M, M and Hughes, A (2014) "Career Development for College Students with Asperger's Syndrome'. *Journal of Career Development*. Vol. 41, No. 3, pp.185-198.

National Autistic Society (2016). *The autism employment gap: Too Much Information in the workplace*. (Online).

Accessed at: <https://www.autism.org.uk/get-involved/media-centre/news/2016-10-27-employment-gap.aspx> (20th September 2018).

National Autistic Society (2018) www.autism.org.uk. Accessed at: 20th September 2015.

Nuehring, M, L and Sitlington, P, L (2003) 'Transition as a Vehicle: Moving from High School to an Adult Vocational Service Provider'. *Journal of Disability Policy Studies*, Vol. 14, No. 1, pp. 23-35.

Nicholas, D, B., Hodgetts, S., Zwaigenbaum, L., Smith, L, A., Shattuck, P., Parr., Conlon, O., Germani, T., Mitchell, W., Sacrey, L and Stothers, M, E (2017) 'Research Needs and Priorities for Transition and Employment in Autism: Considerations Reflected in a "Special Interest Group" at the International Meeting for Autism Research'. *Autism Research*, Vol. 10, pp. 15-24.

Nichols, S., Moravcik and Tetenbaum, S, P (2009) *Girls Growing Up on the Autism Spectrum*. London: Jessica Kingsley Publishers.

Norwich, B (2006) 'Inclusion: Is it a matter of evidence about what works or about values and rights?' *Education 3-13*, Vol. 33, No. 1, pp. 51-56.

OECD (Organisation for Economic Cooperation and Development) 2011. *Inclusion of Students with Disabilities in Tertiary Education and Employment*. Paris: OECD.

Office of National Statistics (2009) Social Trends, No 39 and Data Service (2011), MI reports – Regional Learning Disability/Difficulty Report. (Online). Accessed at:

<https://www.ambitiousaboutautism.org.uk/stats-and-facts>. (20th October 2018)

Ofsted (2012) *Progression post-16 for learners with learning difficulties and/or disabilities*. (Online)

Accessed at: <https://www.gov.uk/government/publications/progression-from-school-for-those-with-learning-difficulties-or-disabilities> (15th December, 2018).

Ofsted (2016) *Moving forward? How well the further education and skills sector is preparing young people with high needs for adult life*. (Online).

Accessed at: <https://www.gov.uk/government/news/high-needs-learners-are-not-always-receiving-the-support-they-need-to-reach-their-potential> (15th December, 2018)

Ofsted (2018) *Further Education and Skills Inspection Handbook*. (Online).

Accessed at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/765965/Further_education_and_skills_inspection_handbook_181 (15th December, 2018).

- Oliver, M (1990) *The Politics of Disablement*. Butterworth: Heinemann.
- Oliver, P (2014) *Writing Your Thesis*. (3rd edition). London: Sage Publications.
- O'Toole, L., Hayes, N and Mhathuna, M, M (2014) 'A Bio-ecological Perspective on Educational Transition'. *Procedia-Social and Behavioral Sciences* 140, pp. 121-127.
- Parsons, S., Guldberg, K., MacLeod, A., Jones, G., Prunty, A and Balfe, T (2011) 'International review of the evidence on best practice in educational provision for children on the autism spectrum'. *European Journal of Special Needs Education*, Vol. 26, No. 1, pp. 47-63.
- Portway S and Johnson, B (2003) 'Asperger Syndrome and the Children who 'Don't Quite Fit'' *Early Child Development and Care*. Vol. 173, No. 4, pp.435-443.
- Preece, D (2002) 'Consultation with children with autistic spectrum disorders about their experience of short-term residential care'. *British Journal of Learning Disabilities*, Vol. 30, pp. 97-104.
- Preece, D and Jordan, R (2009) 'Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support'. *British Journal of Learning Difficulties*. Vol. 38, pp. 10-20.
- Preparing for Adulthood (2013). *Delivering support and aspiration for disabled young people*. Bath: Preparing for Adulthood Programme. (Online)
- Accessed at: <https://www.preparingforadulthood.org.uk/> (10th June 2018).
- Primeau, L, A (2003) 'Reflections on Self in Qualitative Research: Stories of Family'. *The American Journal of Occupational Therapy*, Vol. 57, No. 1, pp. 9-16.
- Reid, B (2011) *Great Expectations*. London: The National Autistic Society.
- Richards, M (2016) "'You've got autism because you like order and you do not look into my eyes": some reflections on understanding the label of 'autism spectrum disorder' from a dishuman perspective'. *Disability and Society*, Vol. 31, No. 9, pp. 1301-1305.

Roberts, K (2010) 'Topic Areas to Consider When Planning Transition from High School to Postsecondary Education for Students with Autism Spectrum Disorders'. *Focus on Autism and Other Developmental Disabilities*. Vol. 25, No. 3, pp. 158-162.

Robinson, C. and Kellett, M. (2004) 'Power' in Fraser, S. Lewis, V. Ding, S. Kellett, M. and Robinson, C. (2004) *Doing Research with Children and Young People*, London: Sage Publications.

Rydzewska, E (2012) 'Destination unknown? Transition to adulthood for people with autism spectrum disorders' *British Journal of Special Education*, Vol. 39, No. 2, pp. 87-93.

Rydzewska, E (2016) 'Unexpected changes of itinerary – adaptive functioning difficulties in daily transitions for adults with autism spectrum disorder'. *European Journal of Special Needs Education*, Vol. 31, No. 3, pp. 330-343.

Schall, J., LeBaron Wallace, T and Chhuon (2016) "'Fitting in" in high school: how adolescent belonging is influenced by locus of control beliefs', *International Journal of Adolescence and Youth*, Vol. 21, No. 4, pp. 462-475.

Scott, L (2016) *SEND: The schools and colleges experience. A report to the secretary of state for education*. (Online) Available at:

www.gov.uk/government/publications (Accessed 08/01/2017)

Shakespeare, T (2013) *Disability rights and wrongs re-visited*. London: Routledge.

Shepherd, J (2015) "'Interrupted Interviews": listening to young people with autism in transition to college'. *Exchanges: The Warwick Research Journal*, Vol. 2, No. 2, pp. 249-262.

Sicile-Kira, C (2006) *Adolescents on the Autism Spectrum*. London: Vermilion.

Siegel, D, J (2013) *Brainstorm: The power and purpose of the teenage brain*. London: Scribe publications.

Smith, J, A (2003) *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage Publications.

Smith, J, A (2004) 'Reflecting on the development of interpretative phenomenological analysis and its contribution to psychology'. *Qualitative Research in Psychology*. Vol. 1, No. 1, pp. 39-54.

Smith, J, A (2011) 'Evaluating the contribution of interpretative phenomenological analysis'. *Health Psychology Review*, Vol. 5, No. 1, pp. 9-27.

Smith, J, A and Osborn, M (2008) 'Interpretative phenomenological analysis'. In: J, A Smith, ed. *Qualitative psychology: a practical guide to research methods*. London: Sage. (p322-41).

Smith, J, A., Flowers, P and Larkin, M (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Sosnowy, C., Silverman, C and Shattuck, P (2018) 'Parents' and young adults' perspectives on transition outcomes for young adults with autism'. *Autism*, Vol. 22, no. 1, pp. 29-39.

Spyrou, S (2011) 'The limits of children's voices: From authenticity to critical representation' *Childhood*, Vol. 18, No. 2, pp151-165

Stoner, J., Angell, M., House, J. & Bock, S. (2007) Transitions: Perspectives from Parents of Young Children with Autism Spectrum Disorder (ASD). *Journal of Developmental and Physical Disabilities*, 19, No. 1, pp. 23-39.

Swaim, K, F and Morgan, S, B (2001) 'Children's Attitudes and Behavioral Intentions Toward a Peer with Autistic Behaviors: Does a Brief Educational Intervention Have an Effect?' *Journal of Autism and Developmental Disorders*, Vol. 31, No. 2, pp. 195-205.

The Foundation for People with Learning Disabilities (2017) *We Can Dream! – about the project*. (Online)

Accessed at: <https://www.mentalhealth.org.uk/learning-disabilities/publications/we-can-dream> (15th September, 2017)

Tobias, A (2009) 'Supporting students with autistic spectrum disorder (ASD) at secondary school: a parent and student perspective'. *Educational Psychology in Practice*. Vol. 25, No. 2, pp. 151-165.

Todovora, I (2011) 'Explorations with interpretative phenomenological analysis in different socio-cultural contexts'. *Health Psychology Review*, Vol. 5, No. 1, pp. 34-38.

Toor, N., Hanley, T and Hebron, J (2016) 'The Facilitators, Obstacles and Needs of Individuals with Autism Spectrum Conditions Accessing Further and Higher Education'. *Journal of Psychologists and Counsellors in Schools*. Vol. 26, No. 2, pp. 166-190.

United Nations (1989) *Conventions on the Rights of the Child*. New York: United Nations

VanBergeijk, E., Klin, A and Volkmar (2008) 'Supporting more able students on the autism spectrum: College and beyond' *Journal of Autism and Developmental Disorders*. Vol. 38, pp. 1359-1370.

Watson, D. Abbott, D., and Townsley, R (2006) 'Listen to me, too! Lessons from involving children with complex healthcare needs in research about multi-agency services'. *Child: care, health and development*, Vol. 33, No. 1, pp. 90-95.

Weare, K (2015) *What works in promoting social and emotional wellbeing and responding to mental health problems in schools? Advice for schools and framework document*. London: National Children's Bureau.

Accessed at: www.ncb.org.uk/areas-of-activity/education-and-learning/partnership-for-well-being-andmental-health-in-schools/what-works-guidance-for-schools

White, J and Rae, T (2016) 'Person-centred reviews and transition: an exploration of the views of students and their parents/carers', *Educational Psychology in Practice*, Vol. 32, No. 1, pp. 38-53.

Williams, T (2007) 'A study of further education provision for students with autistic spectrum conditions in the Surrey area'. Unpublished report, Surrey and Borders Partnership NHS Trust. (Online)

Accessed at: <http://www.mugsy.org/feasresearch.pdf> (10th November 2018).

Willig, C. (2013). *Introducing qualitative research in psychology*. New York: McGraw-Hill International (2nd Edition).

Wing, L (1996) *The Autistic Spectrum*. London: Robinson.

Wolf, A (2011) *Review of Vocational Education. The Wolf Report*.

World Health Organisation (2018) *International Statistical Classification of Disease and Related Health Problems (ICD-11)*. (Online).

Accessed at: <https://www.who.int/health-topics/international-classification-of-diseases>
(15th January, 2019)

Yardley, L (2000) 'Dilemmas in qualitative health research'. *Psychology and Health*, Vol. 15, No. 2, pp. 215-228.

Appendices

Appendix 1 **Literature search strategy**

The main searches for the literature review took place between September 2016 and May 2017. I continued the searches throughout the study however to ensure that they were as up to date as possible. The databases that I searched were: PsycInfo, Education Resources Information Centre (ERIC), the British Education Index (BEI), Child Development and Adolescent Studies, Web of Science and ETHoS. The search terms I used included:

- Autism, Autis*, Autism Spectrum Disorder, Autism Spectrum Condition, Asperger* syndrome.
- Year 10 / 11/ 12, secondary education, further education, college, further education college.
- Transition, post-sixteen, post-sixteen transition, post-secondary, post-secondary transition.

Once I had undertaken searches of the databases, I undertook a title screen to assess the suitability of the article and if the title appeared to be relevant to the study, I read the abstract.

Table 15: Record of databases searched

Databases searched	Combined search: ERIC, BEI and Child Development and Adolescent Studies	PsycInfo	Web of Science	ETHoS
Numbers screened	1,416	2,217	1,314	10

The inclusion criteria required the following:

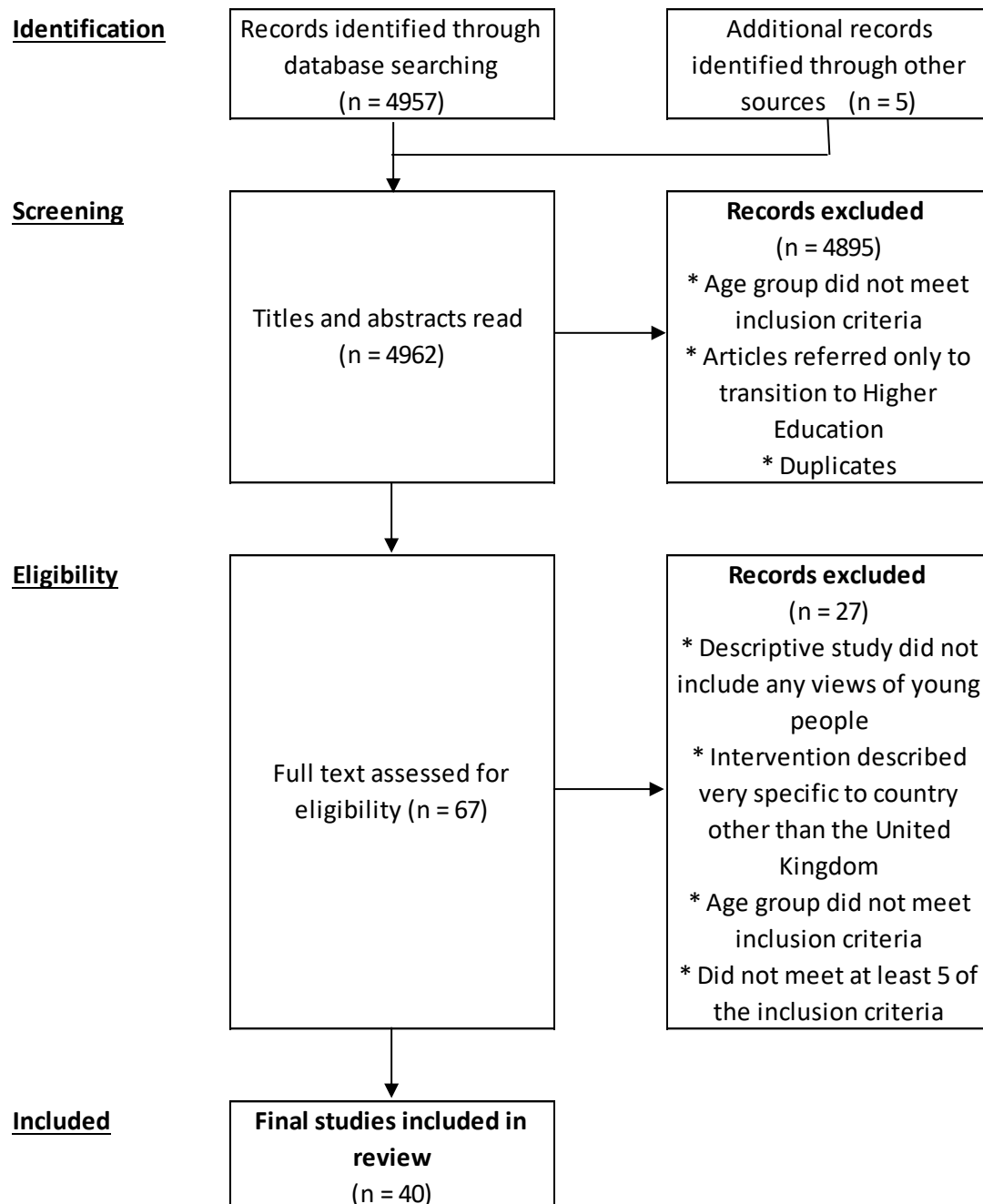
- Studies which refer to young people in their mid-late teens with an autism spectrum disorder.

- Only studies which include the experiences of young people with a diagnosed autism spectrum disorder.
- Studies that include the views of young people.
- Studies that refer to young people moving onto further education.
- Studies that include young people with ASD who are involved in an educational transition.
- Peer-reviewed journal articles.
- Research completed after the year 2000.

Government documents related to this area were searched for on the www.gov.uk website and further statistics affecting this population were found on: www.ons.gov.uk.

This flow diagram illustrates how articles were included and excluded. This is based on PRISMA's four-phase diagram, as adapted from Moher, Liberati, Tetzlaff & Altman, (2009).

Figure 5. Flow diagram outlining the literature review process



Appendix 2**Inclusion Criteria for the Participants****Table 16: Inclusion criteria for participants**

Inclusion criteria	Rationale
Year 11 pupil	The study was a two-part study, the second part involved exploring the experiences of transition retrospectively as well as the participants' early impressions of further education. It was important therefore that the participant would be leaving secondary education in that year.
Diagnosis of an autism spectrum disorder as categorised in the DSM-V (2013)	Young people of this age may have received a range of diagnoses related to autism which were subsumed within the DSM-V (APA, 2013) category of autism spectrum disorder (ASD). It was important to not restrict participation based on past diagnoses.
Young people who were able to verbally engage in the research process and for whom an interview situation was unlikely to cause them a disabling level of anxiety.	<p>The choice of semi-structured interviews meant that it was important that the young people involved were able to engage comfortably in a verbal exchange.</p> <p>I liaised with the Special Educational Needs Co-ordinator (SENCo) and respected the advice of school staff and parents to ensure that this was the case.</p>

Appendix 3

Pre-visit information for potential participants



University of
BRISTOL

Norah Fry Research

8 Priory Road
Bristol, BS8 1TX



In this space I will include a picture of the individual school / name of the school

My name is Jayne Chavez. I am a student at the University of Bristol. I would like to carry out a study on what is it like for young people with ASD to finish year 11 and move onto a new provision. This may mean moving onto sixth form, college or into work-based learning, such as an apprenticeship.

I think that it is important that young people are able to share their experiences. I hope that this project will help adults who support young people with ASD in year 11 to better understand what this time is like for those young people.

I would like to talk to young people about their experiences and this would take place on two separate occasions. The first would be while pupils are still in Year 11 and the second time would be when they have started the next provision ie moved onto Year 12 or started an apprenticeship.

I know that Year 11 will be a very busy year for you with your exams and revision. This research study will take place at times before or after your exams. I can arrange to talk to you in school when you will not be involved in lessons or revision sessions.

I will be arranging with your teachers to visit your school soon to tell you more about the study and explain what would be involved. Participation in the study is entirely voluntary and it is fine if you do not want to be involved. I very much hope that you will think about it. I look forward to visiting your school soon.

Best wishes, Jayne

Appendix 4

Pre-visit letter to parents



University of
BRISTOL

Web: www.bris.ac.uk/Depts/NorahFry/

Norah Fry Research Centre

8 Priory Road
Bristol, BS8 1TX



18/04/2017

Dear parent / carer,

I am a second year trainee Educational Psychologist at the University of Bristol. I am currently on a work placement within As part of my training I am required to complete an extended study in an area of personal and professional interest. In the past I have worked as a Careers Advisor and have also had a range of experience of working with young people with autism. I have therefore chosen to explore the area of post-sixteen transition for students with Autism Spectrum Disorders. I feel that this is an important time in their lives and hope to learn more about it by talking to young people in year 11 about their experiences.

At the present time I am visiting schools and resource bases to meet with school staff and students to explain more about my study. If students may be interested in taking part I will provide them with further more detailed information and consent forms. There will also be copies for parents. Following this, a convenient date will be arranged for the interview to take place.

I am hoping to visit School on Wednesday 3rd May. Can I please ask you to sign this form if you are happy for me to meet with your young person and explain the study to them. You can contact me on: cdxjc@bristol.ac.uk, orif you have any questions about the study.

Kind regards



Jayne Chavez – Trainee Educational Psychologist

I give permission for Jayne Chavez to meet withto discuss her research study

Parent name.....

Signature.....

Date.....

Appendix 5

Letter to Head Teacher



Norah Fry Research Centre

8 Priory Road
Bristol, BS8 1TX



Web: www.bris.ac.uk/Depts/NorahFry/

25/04/2017

Dear,

I am currently a Year 2 trainee Educational Psychologist on placement with..... Educational Psychology Service. As part of my training I am required to complete a doctoral level research study on a subject of personal and professional interest.

My research title is – An exploration of the experiences of post-sixteen transition for students with Autism Spectrum Disorder (ASD).

The purpose of the research is to provide an in-depth understanding of pupil's experiences and perceptions of this period in their lives. I believe that it is important to include the 'voice' of young people within research to better understand how the process is experienced by these young people. I would be interested to hear about any personal strategies or support that have been particularly positive or unhelpful during this time.

I would like to work with pupils in year 11 who have a diagnosis of an Autism Spectrum Disorder. I have met with..... to discuss the study and am writing to ask permission to carry out this research in your school.

The research would involve me meeting students individually in school. I will use a semi-structured interview format and would envisage that interviews would last up to an hour and would take place in May / June, either before or after the exam period. The research project will ensure anonymity and confidentiality of the participants and schools. Participation is entirely voluntary.

Written consent must be received from the young person and their parent, if they are under sixteen years old. Parents will be informed that their child has been asked to be

involved in this research. If during the study, the young person changes their mind, they will be able to withdraw from the research immediately.

The interviews will be audio-recorded. I will transfer this recording into a written format, with all the names of students, teachers and schools altered. The main themes from the student's interviews will form the basis of my final written dissertation, which will be available through the University of Bristol Library.

The research project may be presented to Educational Psychology Service. It is hoped that it will increase understanding of issues around transition which affect young people with autism spectrum disorders and that this will contribute to professional policy and practice in the area.

I will call / email you within the next week to discuss the research and I can answer any questions that you may have. Alternatively if you would like to contact me, I can be contacted via email at: JChavez@somerset.gov.uk or by mobile on: 0799 0084040.

Yours Sincerely

Jayne Chavez – Trainee Educational Psychologist.



University of
BRISTOL

Web: www.bris.ac.uk/Depts/NorahFry/

Norah Fry Research Centre
8 Priory Road
Bristol, BS8 1TX



Participant Information Sheet

Who am I?



My name is Jayne Chavez. I am a trainee Educational Psychologist at the University of Bristol and I am also working forLocal Authority. I have previously worked as a secondary school teacher and as a Careers Advisor.

What is my project about?

The aim of my project is to find out more about the experiences of post-sixteen transition for young people with Autism Spectrum Disorders. I am interested to hear about your experiences when you are still in year 11 and after you have left.

Why is it important?

I am hoping that my project will add to what people already know about how to best support students with ASD as they move from year 11 and into their next provision. This information will hopefully increase understanding of any particular issues which affect students during this time. This may encourage others to develop different ways of helping these students.

What would the project involve?

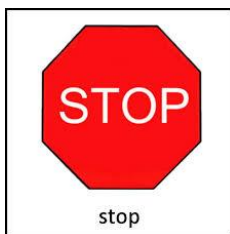
I would like to invite you to meet with me on two different occasions to talk about your experiences. The first time would be in May or June and the second time in October.



Meeting 1 - This will take place in a quiet room in school. If you would prefer to have a teacher in the meeting with you, that's fine. I will ask you questions about school and your likes / dislikes. I will ask you about your future plans and how you have decided upon these plans. I would like to hear what your thoughts and feelings are about the future and the plans that you have made. I am interested to hear if you have received support or advice that has helped or hindered your decision-making. I will also ask you about things that may have helped you in the past and also about plans for your longer-term future.

Meeting 2 – This will take place in your new placement. I will ask you about leaving year 11 and your thoughts and feelings about this. I will ask you about moving on to a different provision, for example, has it been as you expected? Do you think that you've learnt anything from the process?

Meetings will last for up to one hour and will be recorded on an audio-recorder. This will then be transferred into a written format which will be saved anonymously on the computer. This means that your information will be saved under a false name so that no-one, apart from you and me, will know that this is what you said. You can stop the meeting at any time. You can use a STOP card, if you want to.



What would happen if there were too many volunteers?

In the unlikely event that there are more volunteers than needed, participants will be randomly selected. All consent forms will be kept and people contacted if their participation is later required.

Confidentiality

The information I collect will be confidential. This means that I will not talk to other people about what you've told me. This would only be different, if you told me something that made me think that you were not safe in some way. I would then need to discuss it with you and pass on my concerns to a member of school staff.

What will happen to your information?

The information that you share with me will be included in a written report. Your name will not be used in any part of the report. Please also be aware that it is possible to withdraw from the study at any time. You can withdraw your information at any time up until 31st December 2017.



Data protection Act

This Act means that any information that you provide will be kept by The University of Bristol for twenty years. Any information will be kept in writing but will not have your real name on it.

Informed consent

If you have any questions about the research or need more information you can speak to (Head of centre). You can also contact me via email on: cdxjc@bristol.ac.uk. Participation in the project is entirely voluntary, it is fine if you do not want to be involved. If you say that you would like to be involved and then change your mind, that is fine too. You can withdraw any information up until 31st December 2017.

If you would like to be involved in the project can you please fill in the Consent form and return it in the envelope provided by(Date) to (Head of centre) I will then contact..... to arrange to meet with you.

Thank you for taking the time to listen to me today. I hope that you feel able to take part in the research project. I would love to hear about your experience.

Consent sheet for participants



Norah Fry Research Centre
8 Priory Road
Bristol, BS8 1TX



Web: www.bris.ac.uk/Depts/NorahFry/

Tel: 0117 9546755

E-mail:

John.Franey@bristol.ac.uk

Tel: 0799 0084040 (Jayne Chavez,
Researcher

direct)

Email: cdxjc@bristol.ac.uk

Name:..... Date of birth.....

School:.....

Contact telephone number:.....

Email address:.....

Please tick YES or NO to the following statements.

	Yes	No
I have read and understood the Participant Information sheet		
I agree to take part in the research		
I agree that Jayne will digitally record the interviews and then store them in written form in a password protected folder		
I understand that all my information will be anonymised and real names will not be used		
I agree that my information can be used in a written report		
I know that I can change my mind about taking part at any time.		
I know that I can withdraw any of my information up until 31 st December 2017		
I agree to Jayne using my personal contact details to contact me in August. This will be to confirm where I will be based in September and to arrange to meet.		



University of
BRISTOL

Web: www.bris.ac.uk/Depts/NorahFry/

Norah Fry Research Centre

8 Priory Road
Bristol, BS8 1TX



Dear

I am a trainee Educational Psychologist at the University of Bristol and I am also working for the Educational Psychology Service in..... I have previously worked as a secondary school teacher and as a Careers Advisor.

I would like to conduct research into the post-sixteen transition experiences of young people with a diagnosis of Autism Spectrum Disorder who will be leaving Year 11 this year. I am very interested to hear about individual experiences of the process. I would also like to hear if young people have received support or identified particular strategies which have been particularly helpful or unhelpful in managing this process.

Why is it important?

I am hoping that my study will add to information on how best to support students with ASD as they move from year 11 and into year 12. I hope that this information will increase understanding of issues which may affect year 11 students with Autistic Spectrum Disorders during this transition period and that this may help to improve current practice. The study would be divided into two main stages in order to find out about experiences before and after this transition.

What would the study involve?

The study would involve participants in two interviews. The first interview would take place in May / June, either before or after exams and the second interview would be in October. The interviews would be semi-structured and would cover topics around transition. I am interested to hear about how young people have made decisions about their next provision and if they have any longer-term plans for the future. I would like to hear about strategies that the young people may have developed to help them to make choices and also if they have received any support that has particularly helped or hindered their decision-making.

The second interview will hopefully take place in their year 12 placement or at home, with your permission, if that would be preferable. In this interview I will ask them to reflect on their past experience, for example, of leaving year 11 and I will also ask them about their present experience.

Interviews will last for a maximum of one hour and will be digitally recorded. This will then be transferred into a written format which will be saved anonymously. All information will be coded so that it is not identifiable.

How will the information be used?

The information I collect will be confidential. I will not be able to tell you, or anybody else what your child has said. However, if your child tells me about something which makes me think that they or another person are at serious risk. I will inform the appropriate people.

The information that they share with me will be included in the report.

Informed consent

If you have any questions about the research, I am happy to be contacted via email (cdxjc@bristol.ac.uk) or mobile (0799 0084040) and would be willing to meet with you to discuss the project, if you would like to do this. Participation in the project is entirely voluntary and it is possible to withdraw from the study at any time. If your child is under the age of sixteen, and you are happy for them to be involved in the research, can you please sign the attached Consent form and return it in the envelope supplied to(SENCo). With your permission I can then contact the school to arrange a convenient time to meet with your child.

Data protection

The University of Bristol are legally obliged to comply with its duties under the Data Protection Act (1998). Any information that your child provides will be kept confidentially, anonymously and securely on a University of Bristol password protected server. The information provided will be used only for the purpose of the study. Data collected during the study will be stored on a University of Bristol secure server for twenty years.

What should I do if I want to make a complaint about the study?

The study has received ethical approval from the Ethics Committee within the School of Policy Studies at the University of Bristol. If you have any concerns please contact:

John Franey

Norah Fry Research Centre

8 Priory Road

Bristol

BS8 1TX

Tel: 0117 9546755

Thank you for taking the time to read this information.

Jayne Chavez - Trainee Educational Psychologist

Parent consent form



Norah Fry Research Centre
8 Priory Road
Bristol, BS8 1TX



Tel: 0117 9546755
E-mail: John.Franey@bristol.ac.uk

Tel: 0775985 8622 (Jayne Chavez,
Researcher direct)
Email:cdxjc@bristol.ac.uk

Consent form for parents – for students under the age of sixteen.

Please tick Yes or No to the following statements

	Yes	No
I have read and understood the information regarding the research project		
I understand that my child's participation is voluntary and that he/she is free to withdraw at any time for any reasons		
I agree that my child can take part in the study		
I understand that the information that he/she provides will be used by the researcher to write a report on the experience of post-sixteen transition for young people with a diagnosis of Autism Spectrum Disorder.		
I understand that the data from the interviews will be anonymised so that individual contributions cannot be recognised.		
I understand that if I would like to find out further information on the study that I can contact the school or the researcher directly.		
I understand that the information collected during this research will be stored anonymously on a password protected computer.		
I understand that the information will be only be used for the purpose of the study.		

Name of child.....

Signature of parent / carer.....



1. Introductions

Getting to know each other
Hobbies / interests



2. School

Likes / dislikes

3. Year 11

Year 11 so far
Preparation for leaving year 11.
Plans for after year 11
Thoughts and feelings

4. Future plans



Short-term plans
Longer-term plans
Thoughts and feelings

Topic guide for participants



1. **Transition** –
leaving school
leaving year 11
2. **Preparing for college**
How did you prepare?
Thoughts and feelings
3. **Being at college**
Early days
Your course
Likes / dislikes
4. **End of the first term**
After the holiday
Thoughts and feelings



5. **Into the future**
Short-term plans
Longer-term plans

Appendix 9

Interview schedule for pre-transition interview.

- Introduce myself and describe the project – talk through the Participant Information
- Check that participant is still happy to be involved.
- Go through the topic list.
- Show them the STOP card to use, if they wish.

I am very interested in your experiences.

Getting to know you.

Hobbies / interests - in school / out of school

What makes you happy? What's important to you?

School

Experience of secondary school. Likes / dislikes.

Best / worst things about secondary school.

Year 11

Experience of year 11.

Making plans for September. Thoughts and feelings?

Decision-making – Courses / colleges.

Preparations – over the years? In year 11?

What helped / hindered?

Future plans

Short term plans – Leaving year 11 / school. Thoughts and feelings?

Preparations for college.

Views on life at college.

Longer term plans –

Career plans.

Other long-term plans.

Supporting questions

Can you describe that to me?

Can you please explain

How did that make you feel?

Can you tell me a bit more about that?

In what way? Can you tell me more about that?

Appendix 10

Interview schedule for post-transition interview

Interview Schedule for post-transition interview

Remember – Put recorder on

- Remembering last interview – Wanted to meet you in year 11 and then when you had left - I asked you about school, leaving year 11, moving onto year 12 and any longer-term plans that you had.
- Are you still happy to be involved – this will be the final interview
- Go through topic list

I am very interested in your experience, anything that you would like to tell me about it....

Transition

Leaving year 11 – processes. What was helpful / unhelpful? Thoughts and feelings?

Preparing for college

Summer holiday preparations.

Specific preparations.

Being at college

Early days of college.

Experience of course / other experiences.

Likes / dislikes.

End of the first term

After the holiday

Reflections / thoughts and feelings

Into the future

Short-term plans

Course progression

Other plans?

Longer-term plans

Career plans

Other plans?

Supporting questions

Can you describe that to me?

Can you tell me a bit more about that?

Can you please explain

In what way? How did that make you feel?

Appendix 11

'Useful websites' for the participants



Useful websites

Careers

www.nationalcareersservice.direct.gov.uk

<https://www.gov.uk/topic/further-education-skills/apprenticeships>

Exam stress

www.childline.org

Revision tips

www.studenthacks.co.uk

Mental health – Depression and anxiety

www.youngminds.org.uk

www.depressioninteenagers.com

Bullying

www.bullying.co.uk

www.antibullying.net

Drugs advice

www.talktofrank.com

Specific websites for young people with autism – Covers many of the topic areas above and more.....

www.ambitiousforautism.org.uk

www.autism.org.uk

Appendix 12

Example of steps 2 and 3 in data analysis

Step 2

	Original transcript	Exploratory comments
<p>Descriptive comments</p> <p>Linguistic comments</p> <p>Conceptual comments</p>	<p>2'38)</p> <p>Jayne: So, the next bit really is just to talk a little bit about school, and how school has been for you. So, that can really be at any time in your life, but I guess the bit that you will remember most is secondary school.</p> <p>Boy: It's been complicated because this wasn't my first school, my first school was It was fine at the beginning, but...puberty hit..... and then I realised that I had (long pause).....</p> <p>Asperger's, and my anger problems occurred, quite difficult for me, and for a period of time I left school, for a bit. That was for three years, and then three years after I started beginning to re...joining like school life.</p> <p>And, firstly I went to, and secondly, I went here, into the centre... programme.</p> <p>Jayne: So, how long have you been in the..... centre?</p> <p>(03'55)</p> <p>Boy: Erm, I would say two years</p> <p>Jayne: Ok, so you had three years when you were.. you were educated at home?</p> <p>Boy: I would say (long pause) no. There was some kind of education programme, but I wouldn't say it was a proper one.</p> <p>Jayne: Right ok, so when you came back into education...</p> <p>Boy: Yes, I restarted at the beginning</p> <p>Jayne: Ok, and how has that been for you?</p>	<p>Summary of a lengthy period of time before his time in current provision</p> <p>Does he see his anger problems as being caused by puberty or Asperger's? Is this out of his control?</p> <p>Pauses- may indicate reflection on how to explain/ make sense of difficulties. For himself? Or for me?</p> <p>Spoken in a tone without emotion. Is this how he feels about it or a 'style' of speaking?</p> <p>Seems clear with time periods – Is it still fresh in his mind?</p> <p>Very disrupted education</p> <p>Doesn't recognise this period of education as a standard form of education. What is a 'proper' education? A long time to not have this - how would this feel ?</p> <p>Needing to repeat education. Beginning at year 7 level?</p>

	<p>Boy: Erm, it's been stressful but in the end, I was able to accomplish entering exams, maths exams, so...</p> <p>Jayne: Great</p>	<p>Emotional cost. A feeling of success. Accomplished - what does it mean to him using this word. Does he feel that his success is in entering the exams and not passing them? In the end – year 11 as the 'end' of something. Is this part of his journey over?</p> <p>A need to explain how difficult it has been.</p> <p>Metaphor – why a journey?</p> <p>In what ways was it hard</p>
--	--	---

Step 3

Emergent themes	Original transcript	Exploratory comments
<p>Descriptive comments</p> <p>Linguistic comments</p> <p>Conceptual comments</p> <p>Difficulties of Puberty/ adolescence</p> <p>Understanding of Asperger's and its relationship to his difficulties</p> <p>Taking time to find the right place</p> <p>A unique experience of school life</p>	<p>(2'38)</p> <p>Jayne: So, the next bit really is just to talk a little bit about school, and how school has been for you. So, that can really be at any time in your life, but I guess the bit that you will remember most is secondary school.</p> <p>Boy: It's been complicated because this wasn't my first school, my first school was It was fine at the beginning, but...puberty hit..... and then I realised that I had (long pause).....</p> <p>Asperger's, and my anger problems occurred, and for a period of time I left school, for a bit. That was for three years, and then three years after I started beginning to re...joining like school life. And, firstly I went to, and secondly, I went here, into the centre... programme.</p> <p>Jayne: So, how long have you been in the..... centre? (03'55)</p> <p>Boy: Erm, I would say two years</p>	<p>Summary of a lengthy period of time before his time in current provision</p> <p>Does he see his anger problems as being caused by puberty or Asperger's? Is this out of his control?</p> <p>Pauses- may indicate reflection on how to explain/ make sense of difficulties. For himself? Or for me? Spoken in a tone without emotion. Is this how he feels about it or a 'style' of speaking?</p> <p>Seems clear with time periods – Is it still fresh in his mind?</p> <p>Very disrupted education</p>

Purpose of education	Jayne: Ok, so you had three years when you...were you educated at home?	<p>Doesn't recognise this period of education as a standard form of education. What is a 'proper' education? A long time to not have this - how would this feel ?</p> <p>Needing to repeat education. Beginning at year 7 level?</p> <p>Emotional cost. A feeling of success. Accomplished - what does it mean him using this word. Does he feel that his success is in entering the exams and not passing them? In the end – year 11 as the 'end' of something. Is this part of his journey over?</p> <p>A need to explain how difficult it has been.</p> <p>Metaphor – why a journey? In what ways was it hard ?</p>
Hls view of education	Boy: I would say (long pause) no. There was some kind of education programme, but I wouldn't say it was a proper one.	
Emotional journey	Jayne: Right ok, so when you came back into education... Boy: Yes, I restarted at the beginning	
Successful outcomes	Jayne: Ok, and how has that been for you?	
Life as a journey –	Boy: Erm, it's been stressful but in the end, I was able to accomplish entering exams, maths exams, so...	
End of a challenging journey	Jayne: Great	

Appendix 13

Email confirming ethics approval

Wed 22/03/2017, 11:42

Jayne Chavez;

SPS Ethics Applications Mailbox

Inbox

Hi Jayne

Thanks for chasing me, I had indeed missed your recent response.

Thanks for submitting your application for ethical approval to the SPS REC, and for responding to comments, regarding your study: *An exploration of the experience of post-sixteen transition for young people with Autism Spectrum Disorders*. (SPS REC 16-17.B10)

Please take this email as confirmation of ethical approval from the SPS REC. If you require a formal letter of approval, please contact Zaheda.

Please let me know if your research plan changes, you may need an amendment to your ethical approval. You wouldn't need to tell us about changes to the training as you don't need approval for this.

Good luck with your research

Beth